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‘I’ve never been surrounded by so many people and felt so alone’: A Heideggerian phenomenological study investigating patients’ experiences of technology in adult intensive care

Louise Caroline Stayt BSc (Hons), PGDip, RN, MSc

Thesis presented in fulfilment of the requirements of the degree of Doctor of Philosophy

The University of Warwick
Faculty of Social Sciences
School of Health and Social Studies

March 2012

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I would like to thank my supervisors, Professor Kate Seers and Dr. Liz Tutton for their support, encouragement, guidance and inspiration.

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Abstract

'I've never been surrounded by so many people and felt so alone': A Heideggerian phenomenological study investigating patients' experiences of technology in adult intensive care

Research Question

What are patients' experiences of technology in adult intensive care?

Research Objectives

- To explore patients' perceptions of receiving care in a technological environment
- To explore patients' perceptions of how technology has influenced their experience of care

Background

Technology is fundamental to the physical recovery of critically ill patients in intensive care (ICU), however, there is a suggestion in the literature that its presence may dehumanise patient care and distract the nurse from attending to patients' psychosocial needs. Little attention has been paid to patients' perceptions of receiving care in a technological environment. The purpose of this research, therefore, was to explore patients' experiences of technology and care within ICU.

Methods

This study was informed by Heideggerian phenomenology. The research took place in a university hospital in England. Nineteen participants who had been a patient in ICU were interviewed using a semi-structured approach. Interviews were transcribed *verbatim* and analysed utilising Van Manen's framework.

Findings

Resulting themes were 'My Useless Body' which describes how participants experienced their body as dysfunctional, disconnected and invaded by technology, 'Making Sense of It', which describes how participants rationalised their experiences by constructing a story, and 'Technology and Care', which describes how and why participants endured technologies in ICU.

Conclusions

The disintegrated body is central to the critically ill's experiences in ICU. Families play an important role in helping patients make sense of their experiences by filling in gaps in memory and helping them to sort the real from unreal memories. Families therefore require support and information resources in fulfilling this role. Patients experience technology and care as a series of paradoxical relationships: alienating yet reassuring, uncomfortable yet comforting, impersonal yet personal. Nurses maintaining a close and supportive presence and providing personal comfort and care may minimise the invasive and isolating potential of technology

Abbreviations

CAM-ICU	Confusion Assessment Method for ICU
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DoH	Department of Health
EQ-5D	Euro Quality of Life 5 Dimensional questionnaire
ET Tube	Endotracheal tube
HR-QoL	Health related quality of life
ICU	Adult Intensive Care Unit
MeSH	Medical Subject Headings
NICE	National Institute for Health and Clinical Excellence
NG	Nasogastric
PTSD	Post-traumatic Stress Disorder
SF-36	Medical Outcome Survey Short Form-36
Trachy	Tracheostomy

Chapter 1: Introduction

Background

Technology influences all aspects of how humans live, work, eat, drink, socialise and how we encounter and manage health, disease, and death. Technology is never more present in the management of disease than in critical care. When entering a critical care area such as an intensive care unit (ICU), the presence of technology is distinctive - seriously ill patients and their relatives are surrounded by technical tools in a high-technology environment (Almerud *et al.* 2008). In order to manage a patient's life threatening condition, complex technologies such as ventilators, monitors, infusions, and pharmaceuticals are frequently used (Wikström *et al.* 2007). The use of these technologies has implications for the way care is both delivered and received (Zitzelsberger 2004). Technology is incorporated in the care of critically ill patients and intensive care and management of critical illness is, to a great extent, dependent on technology.

Life threatening illness not only has a physical impact but may also influence a patient's social and psychological well being. Psychological disturbances such as anxiety and depression are frequently reported after a life threatening illness (Dyer 1995a; Granberg *et al.* 1996; Granberg *et al.* 1998; Russell 1999; McGuire *et al.* 2000; Ely *et al.* 2001; Hewitt 2002; Roberts 2004). Delays or impairment of patient recovery as a result of anxiety and depression have been frequently reported in critical care survivors (Dyer 1995b; Granberg *et al.* 1996; Granberg *et al.* 1998; Russell 1999; McGuire *et al.* 2000; Ely *et al.* 2001; Hewitt 2002; Roberts 2004).

ICU delirium may occur after critical illness (Granja *et al.* 2005). ICU delirium is an acute and sudden decline in attention focus, perception and cognition (Hull and Cuthbertson 2007; Arend and Christensen 2009; Morandi and Jackson 2011). Symptoms include inattention, disorganised

thinking, agitation, inability to converse, disorientation, and memory deficit (Hewitt 2002). Occurrence of delirium is associated with increased mortality and morbidity, duration of ICU stay and cost (Ely *et al.* 2001; Hewitt 2002).

Post Traumatic Stress Disorder (PTSD) has also been reported in survivors of critical illness (Hatch *et al.* 2011). PTSD is a severe ongoing emotional reaction which may develop after exposure to an extreme terrifying event, such as critical illness, that threatens or causes grave physical harm (Friedman *et al.* 2007; Hatch *et al.* 2011; Samuelson 2011). Symptoms include anxiety, depression, nightmares, withdrawal and insomnia. The development of PTSD has severe implications for patients' psychological recovery and well being both in ICU and after discharge from ICU and hospital (Schelling *et al.* 2002; Samuelson *et al.* 2007).

The aim of care in ICU is therefore not only to treat and manage physical symptoms but to also support the social and psychological well being of patients. Nurses play a key role in managing both the physical and psychological care of patients (Hofhuis *et al.* 2008). Previous research suggests that the presence of lots of technology distracts nurses from the social and psychological care of patients (Chesla 1997; Barnard and Gerber 1999; Granberg *et al.* 1999; McGrath 2008). There is a suggestion that technology may impersonalise or dehumanise care (Walters 1995; Alasad 2002). In particular, many authors suggest that the presence of technology restricts the nurses' focus on the patients' social and psychological needs (Chesla 1997; Granberg *et al.* 1999; Barnard and Sandelowski 2001; McGrath 2008). Chesla (1997) and McGrath (2008) suggest that nurses in ICU favour managing technology and the physical aspects of care rather than getting involved with more personal and psychological care. There has been much exploration of the nurses' relationship with technology and how nurses reconcile

technology with care, however, little attention has been paid to the patients' relationship with technology. In particular the patients' perception of how technology influences the care that they receive within a technological environment, such as intensive care, has not been explored. Whilst the nurses may perceive technology as dehumanising the care they deliver it is not known if the patient agrees. The aim of this study was therefore to explore the patients' experiences of technology within the context of their care in ICU.

This study focuses on the experiences of 19 patients who spent a minimum of four days in ICU. A Heideggerian phenomenological approach was utilised to investigate participants' recollections of their experiences of technology in ICU between 3 and 7 months after discharge from ICU. The following thesis presents the details of this study.

Outline of the thesis

A brief outline of the thesis is detailed below:

- Chapter 2: Literature Review

The literature review chapter aims to place the study within the context of the current evidence base with consideration of empirical research, and philosophical, theoretical and clinical perspectives. The discussions highlight the limitations of the existing evidence base providing justification for further study. The chapter is organised into two main sections. The first section aims to define technology. Primarily, the philosophical perspectives of technology are considered and then research literature relating to technology and nursing, patient care and critical care is explored. The second section of this chapter is concerned with patient experiences of critical care and critical illness. The stressors associated with critical illness and

ICU admission are examined and the outcomes of these stressors such as delirium, post-traumatic stress disorder and health-related quality of life are discussed.

- Chapter 3: Research Methodology

This chapter aims to provide an overview of the philosophical and methodological positions that underpin this study. Naturalism is presented as an appropriate paradigm from which to approach this research. Various naturalistic approaches are explored with their advantages and disadvantages discussed. The choice of adopting Heideggerian phenomenology as a methodology is justified by discussing how this approach may best fulfil the aims of this research study. The key tenets and the implications for research are discussed with limitations being highlighted.

- Chapter 4: Research Methods

The research methods chapter describes the practical methods adopted in this project. Interviews, as an apposite means of data generation, are discussed and the nature of phenomenological interviews is characterised. Access and sampling and Van Manen's approach to data analysis are described. Finally, the measures adopted to ensure good quality, rigorous and ethical research are described.

- Chapter 5: Findings

The generated themes are presented in the findings chapter. The key three themes are 'My Useless Body', 'Making Sense of It' and 'Technology and Care'.

- Chapter 6: Discussions

The discussions chapter evaluates the generated themes with reference to the current evidence base. Findings which are supported by other research literature or indeed refute other literature are identified. Care is taken to describe what the findings add to the evidence base. Novel findings are highlighted and their significance discussed.

- Chapter 7: Conclusions and Recommendations

Finally conclusions are drawn and implications and recommendations for clinical practice based on the research findings are suggested. Areas for further research are also proposed.

Chapter 2: Literature Review

Introduction

In human lives, technology influences all aspects of how we live, work, eat, drink, socialise and how we encounter and manage health, disease, illness and death (Zitzelsberger 2004). Society has entered a technological age in which science and technology are completely integrated with the society in which they operate (Dean 1998). Ihde (1993) contends that human existence is 'technologically textured' which denotes how entwined our activities are with technologies (Walters 1995a).

Increasingly, technology is a pre-eminent tool used in the management of illness, which has implications on the way in which care is both delivered and received. In Western societies, the current default response to illness and disease even impending death is to employ life saving, preserving or prolonging technologies (Timmermans 1998). Health care technologies that intervene, systemise and alter courses of health and illness have become a vital part of health care provision in western societies (Zitzelsberger 2004). The use of numerous and various technological interventions and equipment are common and often viewed as solely beneficial for sustaining or enhancing life (Zitzelsberger 2004). Life saving and sustaining technologies are never more present as in intensive and critical care settings. Technology is fundamental to the care of critically ill patients to the extent that the existence of intensive and critical care depend on it.

This review of the literature offers critical reflection on the essential nature of the relationship between technology and nurses, patients and intensive care. The intention of this review is to provide an overview of the current literature, including literature from disciplines other than

nursing. It focuses on key aspects of technology, nursing, intensive care and patient experiences that relate to this study. The literature review also constructs a preliminary framework upon which to base the interpretation of data in later chapters.

Search Strategy

The literature reviewed in this chapter was identified through electronic databases such as Web of Science, CINAHL, PubMed, Medline and Social Science Citation Index. Free text and Medical Subject Headings (MeSH) search terms were utilised and included technology, nursing, nursing care, critical care, intensive care. Literature pertaining to specific subject areas, such as delirium, sleep, and health-related quality of life was sought using subject specific search terms. Additional material was identified through examining references cited in relevant articles and a hand search of key journals. A more detailed search strategy is included in appendix 6.

Chapter Structure

Review of the literature has highlighted a number of key topics which characterise the nature of technology and patient experiences in ICU. Identified topics are:

- Technology and Philosophy
 - Technology and Positivism
 - Technology and Naturalism
 - Technology and Heidegger
- Technology, Nursing and Care
 - Technology and Care
 - Technology and care- a paradoxical relationship
 - Technology and Nurses Time

- Dehumanisation and fragmentation of care
 - Expertise and competence
 - Paradoxical relationship between technology and/ or care- a futile argument
- Technology and Critical Care
 - Role of Technology in Critical care
 - Technological competency and knowledge
 - Comforting the patient, managing technology and balancing care
- Patient experiences of ICU
 - Stressors in ICU
 - Outcome of Stressors in ICU
 - Long-term Recovery and Health Related Quality of Life

Technology and Philosophy

Numerous attempts have been made to define technology. Arguably technology is not a simple phenomenon to understand or define attributable to its multifarious role and function within society. Barnard (1999) suggests that technology may be understood as a complex interrelationship between numerous influential characteristics that include machinery, equipment, chemicals, people, organisations, science, culture, gender, values, politics, economics, ethics, organisational management and human behaviour and politics. The purpose of this section is to attempt to offer a definition of technology by way of exploring the characteristics of technology within the context of different philosophical paradigms as applied to modern health care. Conceptualising technology within a philosophical framework allows an appreciation of the diverse nature of technology within healthcare.

Technology and Positivism

A positivist paradigm assumes a realist ontology where reality is considered to be an external phenomenon which impinges upon the consciousness of the individual (Neale 2009). Objectivism is the affiliated epistemological view whereby reality exists independent of the mind and the observers' *a priori* conceptual-taking, and be viewed with total detachment (Johnson 2000). Technology therefore may be considered as existing as an objective entity detached from the social or historical context within which they occur. Consistent with these positivist tenets, attempts have been made in the literature to reduce and objectify healthcare technologies. Many authors refer to technology as novel drugs, equipment, devices, techniques and procedures used by health care professionals to provide care (Cook and Sibbald 1999; Sandelowski 1999b; Marden 2005). Wikström *et al.* (2004) asserts that technology means machinery, medical treatment, documentation systems and associated skills to handle them. A positivist view of technology would also suggest a causal-mechanistic relationship between technology and the human body where application of a certain technology will have measureable physiological effects. This infers that the key purpose of health care technologies is to intervene in and manipulate the function of the body which Zitselsberger (2004) suggests may lead to the mastery of disease, illness and death.

A positivist philosophy of technology may be exemplified with consideration of a sphygmomanometer. A sphygmomanometer may be viewed simply as a device for measuring a person's blood pressure. The fundamental function of a sphygmomanometer is to obtain a physiological measurement of blood pressure which may be seen as an objective indication of a person's health, independent of the thoughts, beliefs and attitudes of the individual or the social, historical and cultural context within which the measurement is taken.

Considering technology from a purely realist ontology and objective epistemology offers a restricted perspective on technology and does not adequately characterise technology and its role within the health care setting and in particular its relationship with nurses and nursing care.

Technology and Naturalism

It is suggested within the literature understandings of technology may be subject to social, historical, cultural and gender bias (Barnard and Gerber 1999; Little 2000; Barnard and Sandelowski 2001; Lee 2004). Barnard (1999) goes onto suggest that technology may also be understood in relation to knowledge, skills, associated with its use, repair, design, and assessment. Barnard and others views (Little 2000; Barnard and Sandelowski 2001; Lee 2004) are consistent with a naturalist paradigm. A naturalist paradigm asserts that reality is a mental construction created by an individual within a social context where multiple constructions and interpretations are possible. Knowledge is therefore embedded within a historical, social, and cultural setting and is inherently subjective and contextual (Van der Zalm and Bergum 2000; McConnell-Henry et al. 2009). This ontological perspective is known as relativism (Annells 1999). Technology may therefore be viewed as a social construct that is inseparable from and embedded within the user and social, historical and cultural context. Full appreciation of technology within a complex context such as healthcare and nursing, which is in itself is a rich social, cultural and historical context, may only be achieved if the assumptions of relativist ontology are up held and multiple realities appreciated.

The simple sphygmomanometer within naturalistic philosophy may therefore be appreciated not just as an instrument used to measure blood pressure but understood within the context of its purpose and the social framework within which it is used. Arguably a sphygmomanometer used to

measure a patient's blood pressure may also be understood in terms of a care intervention or a therapeutic interaction between nurse and patient within the context of the caring process. A naturalistic philosophy recognises that the physical task of measuring a blood pressure with a sphygmomanometer is embedded within a metaphysical and transcendental reality that exists between the nurse and patient.

The naturalistic paradigm acknowledges the existence of multiple realities. As such the sphygmomanometer may be experienced differently by different people in different settings. Individuals will therefore construct their own understanding and meaning of a sphygmomanometer. Essentially the sphygmomanometer offers a physiological measurement of blood pressure however, a patient may experience this process as an opportunity to interact with nursing staff, a reassurance of their well being, evidence of being monitored or even 'cared-for'. Assessment of patient's vital signs has been the domain of the skilled nurse and assessment of blood pressure as a nursing intervention has many connotations regarding the nurse's status, skill and expertise. Barnard (1999) suggests that technologies are understood in relation to knowledge skills and technique and even purports that knowledge and skills are as much technology as the objects themselves. Without the appropriate knowledge and skills a machine has little meaning or use (Barnard 1999). A sphygmomanometer is little more than plastic, metal, rubber tubing without the knowledge and skills to use it.

Technology and Heidegger

Martin Heidegger (1889-1976) pioneered a new way of thinking about technology (Waddington 2005) and is considered to be the forerunner in the development of the philosophy of technology (Ihde 1993). Zitelberger (2004, Page 242) heralds Heidegger as offering a 'radical way of thinking about technology through developing an inquiry that uncovers technology's

essence of revealing'. Little (2000) suggests that by considering technology from a Heideggerian perspective its relationship to nurses and nursing may be re-conceptualised.

Heidegger purports that technologies may only reveal its genuine meaning in terms of its purpose (Waddington 2005). Heidegger referred to this as 'authentic meaning' (Heidegger 1962). Heidegger describes equipment or technologies as, 'something in-order-to' where one employs a technology in order to achieve a task. Therefore technology is understood in terms of what task it might achieve. Heidegger utilises the example of a hammer which might be employed to hammer a nail into a piece of wood. The hammer is understood in terms of its functionality (hammering) rather than what it is (a wooden handle with a metal head) (Brassington 2007). Using the hammer signifies the action of functionality not the hammer itself.

Heidegger's 'authentic meaning' is endorsed by Dreyfus (1997) who states that equipment is defined by what it is normally used for by a normal user in a culture where such objects have an established function (Little 2000). Barnard and Sandelowski (2001) also suggest that perceptions of technology depend on how individual technologies are used and operate in specific user contexts. A sphygmomanometer therefore is not approached in a flat, detached manner. The physical properties of a sphygmomanometer are not the first thing appreciated by a person. Rather, one appreciates the sphygmomanometer in terms of its intended purpose. Johnson (2000) suggests that humans look ahead and know that there is a purpose for which they need a tool and understand that this object, in this instance a sphygmomanometer, is useful for that purpose. This would suggest that the sphygmomanometer implicitly means something that is beyond itself. In other words a sphygmomanometer '*means*' blood pressure measurement, patient assessment, monitoring, care intervention among others. Therefore for every object or piece of technology

there are associated purposes and goals which whilst explicitly are absent are very much present within perceived meaning.

Heidegger expands on his explanation of how technology exists in our everyday world and describes three modes of interaction between humans and technology (Waddington 2005). Heidegger refers to these modes as ready-to-hand, un-ready-to-hand and present-to-hand (Heidegger 1962). Referring to Heidegger's example of the hammer, ready-to-hand is when the tool disappears from the user's consciousness as they are focussed on the achievement of the task- hammering a nail into wood. The tool or hammer becomes invisible as a separate entity but almost is viewed as an extension of the hand (Almerud-Osterberg 2010). Technology therefore becomes embodied within everyday practice where technology becomes inseparable from the activity itself (Walters 1995a; Little 2000; Waddington 2005). Similarly, a sphygmomanometer becomes inseparable from the act of taking a blood pressure measurement. During this mode of interaction equipment is unnoticed as people carry out everyday tasks.

When technology or equipment malfunctions, which disrupts normal everyday activity, Heidegger states that the mode of interaction changes from one of ready-to-hand to one of un-ready-to-hand (Heidegger 1962; Paley 1998; Johnson 2000). For example if the handle of the hammer breaks whilst hammering, the dysfunctional tool is propelled into the users' conscious awareness. Likewise, when a sphygmomanometer is broken, faulty or even missing the technology becomes more apparent to the individual since the purpose and goal associated with that piece of technology (blood pressure measurement) cannot be fulfilled.

Present-to-hand is described as a deficient mode of interaction where everyday activity ceases and equipment is viewed in a decontextualised, theoretical way (Benner 1994; Johnson 2000; Paley 2000). This might be how a patient who had never had their blood pressure taken might view a sphygmomanometer when seeing one for the first time. Since the purpose and function of the technology is not known to the patient they are unable to understand it in those terms. They therefore might appreciate the technology in a decontextualised way.

Many authors contend that expert nurses relate to technology as ready-at-hand, where technology blends into the background and becomes subsumed in the process of caring (Walters 1995a; Johnson 2000; Little 2000). Through a process of familiarisation, knowledge and skill acquisition technology ceases to be obtrusive and assumes phenomenological transparency, the status of technology being transformed from one of un-readiness-to hand to one of readiness-to-hand (Little 1999). A student nurse learning how to measure a blood pressure using a sphygmomanometer will be conscious of the sphygmomanometer as a piece of technology, its workings, function and mechanics. As a student becomes more familiar with the technology, the sphygmomanometer will become intrinsic to the process of measuring a patient's blood pressure.

Heidegger in later years sought to further explicate the essence of technology and humanity's role of being within his seminal paper 'The Question Concerning Technology' first published in 1954 (Heidegger 1977). In this contentious piece of work, Heidegger warns of the danger of technology suggesting that the essence of technology may prevent us from having a proper understanding of our own being, or essence. According to Heidegger, technology may be understood as a means to an end and as a human activity, the purpose of which is to gain maximum efficiency for efficiency's sake (Waddington 2005). He refers to this as an

instrumental definition of technology. As such, we will only see nature and people as a resource for the achievement of maximum efficiency. In other words, everything, man, nature, the world is a standing-reserve awaiting use (Dreyfus 1997). This process Heidegger referred to as *Gestell* or enframing (Heidegger 1977). Heidegger's concern is that being enframed by technology restricts our way of thinking. While ever we are enframed by technology, we are unable to appreciate other modes of being in particular the more existential, creative and artistic modes of being (Dreyfus 1997). Heidegger, in his essay, invites us to question technology; 'We shall be questioning concerning technology, and in so doing we should like to prepare a free relationship to it' (Heidegger 1977, Page 50). In other words, by questioning technology and recognising its enframing potential we may free ourselves from this limited world view and 'experience technology within its own bounds' (Heidegger 1977, Page 50). With consideration to health care technologies, Heidegger's philosophy suggests health care professionals are in danger of being blinded by the efficiency of purpose that technology proffers and loose sight of other perspectives- perhaps the humanistic and interpersonal aspects of healthcare.

Heideggerian phenomenological philosophy provides an alternative perspective on the technological environment of modern health care systems and offers a means to reconceptualise its most fundamental relationship to nursing practice and by implication the care that patients receive.

Technology and Critical Theory

Critical Theory originated from the works of several generations of German philosophers and social theorists such as Habermas, Horkheimer and Adorno, in the Western European Marxist tradition known as the Frankfurt School. According to these theorists, critical theory may be

distinguished from a traditional theory as it seeks human emancipation, 'to liberate human beings from the circumstances that enslave them' (Horkheimer 1982, Page 244). In keeping with its Marxist roots, critical theorists suggest that knowledge and understanding is embedded within socio-political context and is generated as a means of effecting social change, empowerment and emancipatory political aims (Campbell and Bunting 1991, Page 4). A core assumption of critical theorists is that certain members of a society are oppressed and subject to inequalities. Considering technology from a critical theorist angle may enable examination of power imbalances and political motivations of technology within healthcare.

Technology is often associated with power within health care systems as political, economic and administrative policies may influence its availability and application. Technological activity may influence practice, roles and responsibilities and the way we organise patient care. Doering (1992) suggests that technologies contribute to the structuring and localising of health and work practices by configuring how people interact and share information. Poland et al. (2005) suggest that technologies act as inescapable mediators in the construction and reproduction of professional identities and in the emplacement of power relations in health and social care.

Technology and knowledge of technologies in healthcare often represents a strategic position within the workplace which maintains the established social hierarchy through the day-to-day activities of the individuals using them (Schiebinger 2003a). Power and knowledge are therefore intertwined (Doering 1992; Rafael 1996). Rafael (1996) suggests that not only are power and knowledge interlinked but are inseparable and mutually generative. The connection between technology, knowledge of technology and power is demonstrated when considering the relationship between the surgeon and the theatre nurse. Specialist surgical equipment such as

(keyhole surgical equipment) is exclusively utilised by surgeons. This specialist equipment and the notion that one must possess a degree of expertise and status in order to utilise and access knowledge about this technology, separates and maintains the hierarchy that exists between nurses and surgeons. Arguably this power relation between nursing and medicine exists due to medicines control of scientific knowledge relevant to both disciplines (Doering 1992). Nurses are only 'allowed' access to a limited amount of knowledge of and limited exposure to certain technologies within health care practice which arguably limits the power that nurses may exert and be perceived as an act of oppression.

Similarly, patients may be subjugated by health care professionals who control access to technologies and knowledge of technologies used in their care (Bennett 2010). Health care professionals' knowledge of technologies is exclusive and they have the power to be selective about the information regarding health care technologies provided to patients which arguably leads to a paternalistic approach to patient care (McCoyd 2011). The exclusivity and associated power of this knowledge of technologies may disempower patients and prevent them from challenging the application of technologies. This suggestion is supported by Doering (1992) who suggests that power limits what is acceptable to be known. In addition technology gives an objective account of disease and illness which prevails over the patients' perspective (Kluge 2011). Poland et al. (2005) suggest that technology has the potential to both empower and disempower its users. Other authors share Poland et al.'s (2005) reservations and suggest that the organisational and managerial structure of modern health care systems is not conducive to the empowerment of neither health care providers nor patients in their care to make decisions regarding the application and development of technologies (Timmermans 1998; Gillick 2007).

The political nature of technology and its influence in health care may be considered from a technological deterministic point of view. Technological determinism is the notion that technology is a driving political force within society (Timmermans and Berg 2003). Technological determinism sees technology as destiny and adopts the underlying assumption that technology is fundamentally harmful (Brynin 2006). Technological determinism suggests that medical technology may function as an institution for social control and propel medical or patriarchal hegemony (Timmermans and Berg 2003; Brynin 2006). As such health care technologies have been accused of providing health care professionals with tools to coerce others into approved healthy lifestyles (Rafael 1996). However, others have suggested that medical technologies offer little agency to either the patient or the physicians and healthcare professionals as the political logic is internal to the technology (Timmermans and Berg 2003). In other words technology itself decides whether and in what way it may be applied.

Conversely social essentialism suggests that technology is neutral and not in itself the cause of oppression but social and workplace structures inhibit people in engaging with the technologies (Aschauer 1999; Jensen and Lauritsen 2005). Social essentialism views technology as a passive blank slate that may only become political through social interpretation and interaction (Faulkner 2001; Schiebinger 2003). Arguably, the organisation of the health service and healthcare delivery operates within a hierarchical and patriarchal framework (Rafael 1996). Timmermans and Berg (2003) suggests that social essentialism consider that technologies function as social catalysts- they are tools that generate interactions or social meanings but do not act, affect, or evolve in themselves.

Both technological determinism and social essentialism are reflected in the technological imperative. The notion of technological imperative has become widespread in the philosophy of health care and suggests that technology has become the paradigm to be applied to all health care challenges (Gillick 2007). In other words, healthcare organisations have sought technological solutions to all challenges and problems- a technological fix. Technology is a basic part of our heuristic and defines the way we see and approach health care problems. Similar to technological determinism, technological imperative suggests that technology has developed a life and identity of its own where technology begets further technology (Walker 2008). Cassell (1993) likened technology to the sorcerer's broom where in the hand of an ignorant apprentice may become out of control. Hofmann (2002), in his discussion paper, also suggests that there is a pathological reliance on technology such that technology have changed from a tool to being a companion and ultimately, to becoming the master of medicine and health care.

Hofmann (2002) describes the imperative of possibility where that which is possible to do has to be done. Health care professionals are expected by fellow colleagues, patients, their families and society as a whole, to try everything possible and are therefore held hostage by the possibilities provided by technology (Kaufman et al. 2011). The analogy frequently cited is that when your tool is a hammer then the world becomes resplendent with nails (Mandell 1983; Benner 2003). Further more there is the imperative of commitment where once applied it becomes more difficult to resist further action and often further technologies (Hofmann 2002).

Arguably patients are also held hostage by technologies. Patients are more educated and aware of healthcare technologies and therefore have greater expectations from healthcare technologies. These expectations lead to a firm belief and trust in the possibilities of technology.

Hoffmann (2002) suggests that patients are satisfied when they are sent for MRI or CT scans or subjected to advanced technological procedures however, appear to be less satisfied when health care professionals deny patients these procedures and only offer low technological interventions such as advice to change diet or exercise more. Patients therefore may feel that they cannot refuse technologies offered, as, like health care professionals, they may believe that they have to try everything possible (Hofmann 2002).

Whether as a result of technological determinism, social essentialism or the technological imperative, ultimately technology has redefined the goals of care in terms of technology. The focus of healthcare has arguably shifted from caring for the sick to diagnosing disease and implementing technological interventions to produce specific outcomes. This technological imperative could therefore be experienced as disempowering and even oppressive.

Summary

The concept of technology has been considered from different philosophical stand points. What is clear within the discussion is that each paradigm has something different to offer to our understanding of technology. A positivist paradigm facilitates an objective appreciation of technology valuing the causal mechanistic qualities of applying medical technologies. A naturalistic philosophy, however highlights that technology may be an individual social construct which is embedded within an individual's social and historical context resulting in multiple interpretations of technology. Heidegger further clarifies our interaction with technology and describes how technology may be understood in terms of its function and use. Heidegger warns how technology may restrict our appreciation of humanistic and creative modes of being.

Critical theory reveals technology as a political and powerful force that potentially disempowers and oppresses both patients and health care professionals.

Conceivably patients in ICU and indeed the nurses caring for them may be influenced by any one these paradigms. The exploration of differing philosophical views of technology may therefore subsequently enable patients' experiences of technology to be placed within a philosophical framework or context. Further clarification of the meaning of technology may be achieved by investigating technology within the specific context of healthcare. The following sections aim to consider technology within the healthcare context whilst acknowledging the different philosophical underpinnings.

Technology, Nursing and Care

Irrespective of the differing philosophical assumptions made about technology, it clearly has a significant impact on nurses and the care they deliver. Arising from the diversity of meaning, the question of how human values are understood to inhabit technology in nursing demands consideration. The following section aims to consider technology within the context of nursing and nursing care.

The impact of technology on contemporary nursing practice is multifaceted and extensive. Locsin (2010) suggests that nursing practice continues to be revolutionised by the impact of technology. Barnard and Gerber (1999) argue that technology appreciably influences nursing history, contemporary nursing practice and its future. Barnard (1999) goes on to explain that technology has transformed nursing practice in the workplace, not only in terms of machinery and equipment, but the skills nurses develop, the knowledge nurses possess, the values nurses

espouse and the significance of nursing to society. Sandelowski (1999b) agrees and suggests that technology in all its manifestation has been integral to and has fundamentally (re) shaped nursing practice.

Technology in patient care represents innovative change and a significant challenge for nurses (Lee 2004). Bunch (2002) suggests that as technology advances, more sophisticated nursing care, treatments and better educated and experienced nurses are required. Barnard and Gerber (1999) agree and suggest that nurses are responsible for an increasingly machinery and equipment orientated healthcare system where complex roles and responsibilities are expanding as a consequence of the emergence of technology.

This change in the role of the nurse in light of technological advances is not viewed as positive by all. Canter (1984) argues that treatment of illness is regarded as being solely a matter of the application of the appropriate technology. He refers to this as the 'technological fix' with the role of the hospital nurse as a 'caring technician' (Wilkinson 1992). Purnell (1998) concurs suggesting that nurses, as a consequence of increasing technology in their work, have undergone a transition from care giver to care taker which has led to a 'hands-off' approach to nursing care. Sandelowski (1999a) also utilises the phrase 'hands-off' approach to nursing care in reference to the consequences of technology.

The term 'hands-off' approach is used, by both authors, as a criticism towards advancing technologies. Indeed the development of sophisticated technologies such as automated monitoring devices mean that the nurses do not even need to touch their patient to take their pulse; telemetry means that the nurse does not even have to be present in the same room.

Superficially, then technology may be seen as leading to a 'hands-off' or distant approach to care delivery. Whether these developments have a negative or positive impact on nursing and nursing care depends upon the individual perception of the nature of nursing and nature of care itself.

The emergence of an increasingly technologically orientated health care system has led to much academic debate regarding technology and nursing. Technology is frequently viewed as something that nurses must work with, and around to make it compatible with nursing care (Barnard and Sandelowski 2001; Marden 2005; Bull and Fitzgerald 2006). Purnell (1998) states that non-nursing technologies are present in but incongruent with a nursing environment which creates what she describes as technologic dissonance. Wiggins (1997) also refers to a 'dissonance' between scientific management and holistic nursing care. Arguably this distinction between technology and care might be considered to be moot. As Sandelowski (1998) points out, the most enduring image of nursing is of Florence Nightingale, the 'lady with the lamp', a woman who with the illumination from a candle assessed and monitored her patients against sickness and deterioration. Nurses now have devices other than a candle to help them see and 'know' their patients in their charge. Therefore arguably technologies (of varying degrees of sophistication) have always been integral to nursing and care.

A great body of literature is devoted to what is frequently described as the 'paradoxical relationship' (Sandelowski 1998; Barnard 1999; Cook and Sibbald 1999; Sandelowski 1999b; Barnard and Sandelowski 2001; Alasad 2002; Lee 2004) between technology and care. This section aims to discuss the concept of nursing care and its 'paradoxical relationship' with technology and the alleged technologic dissonance. The multiple definitions of care are initially

discussed. The research evidence is explored relating to the paradoxical relationship between technology and care. Finally the futility of such a debate is suggested which ultimately offers a substantiated view of technology and care.

Technology and Care

The concept of caring is considered by many to be central to the practice of nursing (Dean 1998; Lea *et al.* 1998; Little 2000), some even consider the two to be synonymous (Dean 1998; Lea *et al.* 1998). Crowden (1994, Page 1106) stated, 'caring is a central and core element of nursing practice'. Ozbolt (1996) agrees suggesting that care is the essence of nursing practice. Conversely Phillips (1993) believes that considering caring as synonymous with nursing is both pervasive and erroneous as it represents an oversimplification of two complex phenomena. Bull and Fitzgerald (2006) also argue that defining nursing purely in terms of caring fails to capture the artistic and human nature of nursing. Whilst many authors are able to articulate why caring and nursing may or may not be synonymous, few offer a definitive definition of either phenomenon. Arguably attempts to provide a definitive definition of nursing and care may lead to a fragmentation of the phenomena. Despite this there is considerable debate in the literature regarding the relationship between caring and nursing and the ways in which they may be defined. As such there exists a great divergence of opinion and debate regarding the definition of nursing care.

The poles of debate about caring in nursing are represented by diametrically opposed paradigms- the existential to positivist. This epistemological debate is reflected in the research methodologies utilised in an attempt to define care and the subsequent theories proposed. Existential theorists include Leininger, Roach and Watson (Spichiger and Wallhagen 2005).

Existential theories emphasise the cultural and interpersonal dimensions of human care and the interrelationship between the nurse and the patient. At the other end of the spectrum positivist theories have been suggested by authors such as Gaut, von Essen and Sjorden and Morse (Morse *et al.* 1990; Sabatino 1999) who attempt to reduce the concept of care into an ordered series of measurable actions, behaviours and activities.

In spite of the various epistemological approaches to defining care, a review of the literature reveals several common themes. It is generally accepted that caring in nursing is not a singular entity and cannot be reduced to quantifiable components. Neither can the concept of caring be adequately described by only existential approaches. Caring spans both the existential and the positivist. Clifford (1995) describes care as having both instrumental and expressive elements. James (1992) similarly divides care into physical and emotional labour and added organisation as a further component of care. Locsin (2010) suggests that in addition to the emotional and physical components of care there is also a cognitive process which reflects the intention of care. In other words, care occurs within a context of purpose and the cognitive process by which that purpose is rationalised, goals are set and actions determined.

The numerous conceptualisations of care show the extent to which the subject has been explored and described. Many of the definitions of care are theoretical formulations of understanding, few are derived from empirical research evidence. The multifarious perceptions of care therefore lead to equally multifarious perceptions of the relationship between technology and nursing care. The following section aims to explore the relationship between technology and care.

Technology and care: A paradoxical relationship

The key theme within the literature is that technology is juxtaposed with the nursing culture of caring. Some authors report that technology and caring are incompatible (Walters 1995a; Barnard 1999; Sabatino 1999; Peacock and Nolan 2000; Bunch 2002; Noh *et al.* 2002; Health 2003; Heath 2003; Lee 2004). Barnard and Sandelowski (2001) identify that there is a theme in the nursing literature which highlights technology as being paradigmatically opposed to humane care and thus is at odds with the practice and moral imperatives of nursing. Frequently the literature presents technology as a mechanistic perspective while referring to caring as a humanistic perspective. Noh *et al.* (2002) acknowledges that technology is frequently viewed as being in the Doctor's domain. Dean (1998) also suggest that technology is seen as being 'medical', 'scientific' or 'curative'. There are many authors who consider the presence of technology to have detrimental consequences on the practice of nursing. In her opinion paper, Purnell (1998) states that the reductionist nature of medicine and technology is in opposition to the holistic intention and practice of nursing. Lee (2004) also suggests that traditionally nursing as a discipline has been care orientated and not concerned with applying technology. This presumed tension or dichotomy between technology and care is referred to frequently within the literature. Review of the literature reveals that this presumed tension may manifest itself in a number of ways: demands on nursing time, dehumanisation, rationalisation and fragmentation of care, and expertise and competence.

Technology and nurses time

A theme within the literature is that technology places demands on nurses' time which detracts them from caring. Sabatino (1999) in her reflective paper, suggest that nurses are finding that the demands for more cost-effective measures including technological advances do not allow

sufficient time to offer personal care for which they have always felt responsible and for many of whom is the reason why they entered the profession. Peacock and Nolan (2000) in their opinion paper also contend that despite advances in technological understanding of disease in the twentieth century the care the individual receive is less. The authors of these, often controversial claims do not substantiate their assertions with any research evidence. Claims are often based on their perceptions of what occurs in practice. However, some qualitative research evidence (Barnard and Gerber 1999; Lee 2004) does suggest that nurses also perceive technology to be draining on their time and a distraction from direct patient care.

Barnard and Gerber's (1999) phenomenological study investigating the understanding of technology in nurses working in surgical areas, revealed that technology makes the daily practice of nursing more demanding, time-consuming and distracted. The authors also reported that technology reduces the nurses' time to establish a nurse-patient relationship and to be involved in personal care. Participants in this study also reported that when technologies are included in clinical practice the patient can become less important than the information obtained from the machinery and equipment (Barnard and Gerber 1999). Echoing these findings, Lee's (2004) qualitative study also found that technologies were perceived to put increased demands on nursing time. Noh *et al.*'s (2002) questionnaire survey of 560 registered nurses in Korea revealed nurses perceive technology as interfering with providing adequate nursing care. Crucially these studies suggest that technology makes the daily practice of nursing more demanding, time-consuming and distracted.

The above studies are based upon self-reporting by nurses, which have shown that they often feel as though they have less time to dedicate to the personal care of their patients. However, it

is arguable that most people when asked about their own performance within their role might complain of a lack of time, perhaps as a pre-emptive attempt to excuse or explain their perceived dissatisfaction or insecurity with their performance within their role. Wiggins (1997) suggests that nurses frequently feel guilty at not being able to deliver what they perceive to be adequate 'care' to their patients. Therefore conceivably nurses perception of 'lack of time' may be a convenient defence mechanism to alleviate their guilt.

Dehumanisation and fragmentation of care

Barnard and Sandelowski (2001) suggest that nurses have charged medical technology with the dehumanisation and objectification of patients' care. Clifford (1995) agrees that there is a danger that the person being cared for undergoes a dehumanising process initiated by illness, hospitalisation and enhanced by the application of technology. O'Keefe (2009) suggests that technology may categorize and marginalize the patients' illness experience. The perceived dehumanisation of care may be further explored with consideration of the research literature. Actual dehumanisation is neither quantified nor adequately defined within the literature however, manifestations of technology which may be interpreted as dehumanised care are evident in some research studies.

There is suggestion that technology places a physical distance between nurse and patient (Hudson 1993; Alexander and Kroposki 2001). Musk (2004) also suggests that technology may deflect nurses' attention away from the patient. The above claims are supported by a grounded theory study conducted by Wiggins (1997). Field work and observations of surgical nurses in their practice noted that technology physically distanced nurses from their patients. Wiggins (1997) highlighted that computer terminals that are frequently utilised for documentation, care

planning, ordering and other essential nursing tasks are often located away from the patient areas. Wiggins (1997) suggested that the physical distance between technologies and the patient may lead to a cognitive dissonance between holistic nursing and technological management. Wiggins' (1997) refers to no compelling evidence to suggest that this dissonance actually does exist. Arguably this assumption could influence the interpretation of the data, however, this is not addressed in the study.

There is also a suggestion that as well as physical barriers, technology may also erect emotional barriers between the nurse and the patient. Ozbolt (1996) suggests that some technologies may impede human interaction. Musk (2004) observed that nurses prefer to be task rather than person focussed in order to protect themselves from their fear of confronting the suffering of others. Johns (2005) also noted that nurses may use technology as a barrier against developing relationships that might be emotionally draining. It would appear that sometimes nurses protect themselves from their fear of confronting the suffering of others (Stayt 2007).

Technology has also been charged with influencing not only the content of care delivery but also its organisation. Enns and Gregory (2007), in their phenomenological study of 10 surgical nurses, suggest that sophisticated technologies contribute to 'tasking' where care was organised into discernible psychomotor tasks. Wiggins (1997) also suggested that routinisation of care at the hands of technology occurred within surgical nurses practice where routine practices common to all were implemented rather than the delivery of holistic individualised care.

Participants of Enns and Gregory's (2007)'s study revealed that attending to technologies made them feel as though the care they delivered was fragmented and aimed only at the body and

not the whole person. Throughout the study report however, Enns and Gregory emphasize that nurse participants lamented the loss of 'caring' in contemporary practice. They conclude that there is a dichotomy between how caring is envisioned and what actually occurs in practice. These findings only represent surgical nurses' perceptions- arguably the recipients of care may perceive it differently.

Dehumanisation of care is a real concern for nurses for whom humanistic, holistic and individualistic care delivery is of paramount importance. Conceivably the perception that care is dehumanised by technology may only be a perception held by health care professions. However research endeavour to ascertain patients' perceptions is seemingly lacking which is a clear gap in our understanding.

Expertise and competence

Ozbolt (1996) suggests that the use of technological equipment may lead to greater expertise of nurses. Barnard and Gerber (1999) in their phenomenological study highlight that knowledge is fundamental to the use of technology and is also a consequence of technology. Arguably the knowledge derived from technology is paramount in the delivery of patient care. Little (2000) identifies the necessity of acquiring technological competence, highlighting that an inability to work in harmony with everyday technology prevents efficient and meaningful practice. Arguably, technology merely changes the skills that are acquired within practice. Barnard and Sandelowski (2001) suggests that technology emphasises some skills and de-emphasises others. Wilkinson (1992) goes as far as to suggest that an over dependence on technology can result in loss of clinical judgement and potential harm to the patient.

Other authors however have a more optimistic view on the potential for technology to influence nursing. It has been suggested that technology improves self esteem, knowledge, decision making skills, efficiency in practice, and augments intelligence (McConnell 1998; Barnard 1999; Little 2000). Barnard and Gerber (1999) suggest that ultimately technology increases the autonomy of nurses and enhances respect from peers and other health care professionals. However, in the same paper, they suggest that technology may alter the free will of nurses as their daily practice is influenced by the demands of technology. Others suggest that technology has been influential in clinical practice, education and the establishment of leadership roles within health care sectors (Johns 2005; Kiekkas *et al.* 2006; Kiekkas *et al.* 2010) increasing the prestige of nursing (Ozbolt 1996) although these accolades appear to be largely based on conjecture rather than evidence.

The Paradoxical Relationship between technology ‘and / or’ care: A futile argument?

The concept of technology ‘and/or’ nursing care sharing a paradoxical relationship assumes that the two are paradigmatically opposed. This polarised perspective adopts a Cartesian viewpoint. Sandelowski (1988) suggest technology and nursing have been understood as irreconcilable opposing forces. Barnard and Sandelowski (2001) identify that even those who espouse the existence of harmony between technology and care have assumed a rapprochement between two separate entities and caution that the continued polarisation of technology and humane care may compromise the distinctive professional identity of nursing. Locsin (1999) also emphasizes the importance of ensuring technology is part of and complementary to caring practices. Sandelowski (1997) highlights that scholarly emphasis on the differences between care and technology has ignored the unity between them. Bull and Fitzgerald (2006) suggest that distinguishing between technologies and caring artificially untangles what are

sophisticated, closely interwoven everyday nursing activities. Many authors agree that there exists a more complex relationship than that of clear incompatibility between technology and nursing care (Sandelowski 1998; Barnard and Gerber 1999; Noh *et al.* 2002; Bull and Fitzgerald 2006; Kiekkas *et al.* 2006).

Arguably engaging in the technology 'and/or' caring debate subjugates the concept of care into a unilateral phenomenon. Care may differ according to the deliverer and recipient of care and the context within which that care occurs. Likewise 'and/ or' protagonists assume technology to be a monolithic entity with no differentiation made among the diversity of technologies, their uses, and purposes. The polarisation of technology and care may be viewed as a social construction. In other words both technology and care are socially shaped. The constructivist view assumes there is a two-way mutually shaping relationship between technology and care in which technology is both a source and consequence of care and vice versa. In other words, within the context of healthcare technology may not be understood without reference to care and care may not be understood without reference to technology. As a result, the social construction of both care and technology is changeable (Appleton and King 2002). Constructivism also rejects technological determinism in particular the view that technologies develop in predetermined directions which then determine social change (Doering 1992). Rather, Constructivism argues that there is an interpretative flexibility about technology and thus its eventual shape which reflects the divergent interests of the different users of that technology.

The constructivist stance therefore challenges the 'and/ or' debate and suggests a mode of perception which encompasses the complexity of the relationship between technology and care.

Sandelowski (1997) contends that technologies fall on a continuum of reconcilability with nursing practice and care and suggests that different technologies are experienced by different individuals within different user contexts. For example heart rate monitors are utilised by training athletes to train within the optimal heart rate zone, whereas health care practitioners may utilise a heart rate monitor to assess a patient's well being.

This constructivist viewpoint of technology and care is reflected in the research evidence. Ray's (1987, Page 170) research on the phenomenon of care in ICU described the concept of 'technological caring' where the nurse blends technological competence with moral experiences and principles. Cooper (1993) in an ethnographic study also demonstrated that technology did not impede care, rather nurses were able to demonstrate technological competence in concert with care. Locsin (2010) based on her extensive research, developed the theory of technological competence as caring which portrays technologies as aspects of care that enable nurses engage patients as participants in their care rather than just recipients.

Barnard (2000) demonstrated in his phenomenological study of 20 surgical nurses' experiences of technology, that nurses cannot use technology without also to some extent being influenced by its use. Arguably the opposite might be true- the perception of technology may be influenced by nursing practice and the context within which it is being used. Dean (1998) suggests that humanity must be preserved alongside technical innovations- as one increases so too must the other with the patient as the focus. In essence when new technology is introduced into society there must be a counterbalancing human response or the technology may have adverse effects (Dean 1998). Therefore consideration of technology and care from a constructivist perspective

renders discussion of the paradoxical relationship between technology and / or care as unhelpful.

Technology and Critical Care

Technology has had a considerable impact on both nursing and medicine, nowhere more so than in critical care (Dean 1998; Locsin 2010). Technology has long since been an integral part of clinical practice in critical care settings (Kiekkas *et al.* 2006) as critically ill patients need specialized treatment and care, which includes support from technology (Alasad 2002; Harrison and Nixon 2002; Wikström and Larsson 2004; Wikström *et al.* 2007). Halpern and Pastores (1999) suggest that the development of new technologies must remain the paramount objective of all critical care areas intent on delivering high-quality and cost effective patient care. Kiekkas *et al.* (2006) assert that the development of critical care nursing has occurred as a result of the increasing use of technology.

Critical care demands technologically proficient care however, nurses on ICU are frequently perceived as being less caring (Locsin 1999). Wikström *et al.* (2007) suggest there is a risk that patients will not be perceived as human beings in a technological environment like critical care. Wilkin and Slevin (2004) agree and warn that the proliferation of technology at such a fast pace may potentially threaten the caring component of critical care nursing. Walters (1995) also suggests that care in ICU may be physically orientated, thereby compromising humanistic care. In contrast it has been suggested that caring is not only possible within the technological world of ICU nursing but that it can be positively enhance knowing the patient, facilitate clinical decision making and improve nurses' expertise (Ray 1987; Cooper 1993; Walters 1995; Walters 1995a; Wilkin and Slevin 2004).

The provision and delivery of highly technological intensive care is both complex and challenging (Walters 1995; Harrison and Nixon 2002). Advancement of knowledge, technological development and management add to the responsibilities of nurses who are required to remain focused on the personal, individualised and human character of nursing practice (Walters 1995a; Harrison and Nixon 2002; Wilkin and Slevin 2004; Wikström *et al.* 2007). These changes have brought with them associated pressures on both nurses and patients (Wilkin and Slevin 2004; Crocker and Timmons 2009; Kongsuwan and Locsin 2011). The use of technology in ICU has provoked much debate which has given rise to much research attention to the nature of caring and the role of technology in critical care environments. Review of the research has revealed several themes regarding the nature of caring in critical care: the role of technology, comforting, technological competence and knowledge, balancing and complications.

Role of Technology in Critical Care

The presence of technology and its role in monitoring and treating the patient is obvious when entering a critical care area however, the meaning health care practitioners ascribe to technology is less clear. Wikström *et al.* (2007) conducted an ethnographic study which studied 12 ICU health care professionals' understanding of technology in their everyday practice in Sweden. Participants reported that they viewed technology as 'Decisive' where technology directs and controls treatment, decision making and patient care (Wikström *et al.* 2007) Participants suggested that the decisive nature of technology contributes to the quality of care that the patients receive both in terms of the sophistication of the technological interventions such as the ventilator and ensuring efficiency of treatment such as the delivery of analgesics and sedatives.

Wikström *et al.* (2007) also identified that technology is 'Facilitating' as it ensured accuracy of monitoring and observations on which clinical decisions are based. Participants expressed reassurance that technology could support or justify their own clinical judgement. This finding is echoed in the earlier work of Alasad (2002) who in a study of a similar design suggested that technology allowed participants to feel 'safe and in control'. Alasad (2002) revealed that with the assistance of technology nurses could know what is happening with the patient. This information was then used to guide therapies to maintain patient safety which gave nurses a sense of control. Wikström *et al.*'s (2007) paper only reported the findings based on the interview data. Findings from the observational field work have yet to be published. It would be interesting to know whether there is parity between the participants reported understanding of technology and their behaviours in practice.

Technological Competency and Knowledge

A key theme within the literature regarding caring in critical care is the importance of technological competency and knowledge. Almerud *et al.* (2008) and Ääri *et al.* (2008) highlight that knowledge and skill based competence incorporating the mastery of technology is essential to the practice of critical care nursing. A key theme within Walter's (1995) Heideggerian study of the life world of ICU nurses was 'being busy' which he described as the nurse's ability to manage the technology skilfully and to perform the technical tasks in a competent manner. Walters (1995) likened 'being busy' as being similar to 'technological competence' described by Ray (1987).

Kongsuwan and Locsin (2011) conducted a hermeneutic phenomenological study in Thailand examining nurses' experiences of caring for patients in technological environment. The authors

found that nurses perceived competency as most significant in their care for the patients using life-sustaining technologies. The nurse participants described technological competency as having the skills, knowledge and experiences needed for effectively using technologies for care. Proficiency with these technologies was seen as an expression of care (Kongsuwan and Locsin 2011). Similarly, McGrath (2008) in her Heideggerian phenomenological study also identified that the nurse participants thought that excellence in nursing care was dependent on the nurses' expertise and technological skill.

Many other researchers highlight 'technological competence' as being a key aspect of the critical care nurses' role. Wilkin and Slevin (2004) suggested that acquiring technological competence helped the nurse gain confidence in care delivery. Kongsuwan and Locsin (2011) expanded this suggestion and identified that nurses who didn't 'know' the technologies felt insecure about their competence and ability to care for a technologically dependent patient. Their study also revealed that not knowing a technology diverted the nurse's attention from the patient to that technology. Almerud *et al.* (2008) also suggest that insecurity about technologies breeds a sense of incompetence. These sentiments had previously been demonstrated in Alasad's (2002) study which revealed that the development of technological competence involves lengthy and stressful stages that he refers to as 'technical orientation' and 'technological culturing'. During these phases nurses focus mainly on machines and not the patient. However, when technological competence has been achieved the machines will be seen as part of the nurses routine care (Alasad 2002). Bull and Fitzgerald (2006) acknowledge the value placed on technical competence, in terms of confidence, respect and professional development as a component of caring. Little (1999) concurs and suggests that in contrast to experienced practitioners who effortlessly integrate technology into their caring practice,

students deliberately focus on technological tasks. These findings correspond with Ray's (1987) and Benner's (1994) early suggestion that technological competence is a fundamental foundation of expertise in critical care nursing.

Comforting the patient, managing technology and balancing care

Despite the prevalence and abundance of technology within critical care and the suggestion that the technical nature of critical care may impede the personal or humanistic side of caring (Walters 1995a; Locsin 1999; Wilkin and Slevin 2004; Wikström *et al.* 2007), there is a strong suggestion within the literature that nurses value the delivery of holistic and humane care.

Kongsuwan and Locsin (2011) suggest that technological competence involves compassionate caring. Nurse participants in McGrath's (2008) phenomenological study describe 'creating a home' for the patient is the essence of caring in ICU. Wilkin and Slevin's (2004) qualitative study revealed that an essential element of caring identified by nurses in ICU was 'comforting'. Comforting the patient involved holistic, physical, psychological social and spiritual care where communication skills, empathy and understanding were cited as being essential. Bull and Fitzgerald (2006, Page 5) in an ethnographic study examining nursing care in technological environments, reported similar findings suggesting that nurse participants emphasized the importance personal care and the 'simple things' like maintaining a patients' dignity, personal hygiene, and comforting. The contribution of the observational data to Bull and Fitzgerald's (2006) theme development is not explicitly disclosed within the research report. Again it would be interesting to see if the semantics corresponded with the behaviour or if nurses were extolling the virtues of personal humane care as arguably it is the socially and professionally desirable opinion to assert.

Kociszewski (2004) demonstrated in a phenomenological study that providing spiritual care, was an important facet of caring within ICU. Kociszewski (2004) identified that nurses felt spiritual care manifested itself in routine listening, touching and comforting. Although not specifically asked about technology and its influence on spiritual care, it might be inferred from these findings that the described approach to spiritual care occurs in spite of the presence of technology.

In contrast, some authors suggest that psychological and personal care may be overshadowed by technology in ICU (Chesla 1997). Kongsuwan and Locscin (2011) describe how their participants found that using technology in ICU distracted their ability to connect with or relate to their patients. This is consistent with Ihde's (1993) philosophy of technology which maintains that it can simultaneously magnify or reduce the dimensions of the human world (Wilkin and Slevin 2004).

Chesla (1997) highlighted an imbalance between technological and humanistic care in ICU. The author adopted an interpretive phenomenological approach, examining 130 nurses from seven hospitals in the USA caring for families of patients in ICU. Chesla utilised focus groups and observations to gather data. The findings suggested that nursing practice within ICU focussed on the biomedical management of the patient. Participants revealed that the nurses' approach to care was a set of curative tasks. Participants within this study failed to acknowledge the personal care of the patient as a consideration, particularly amongst less experienced nurses. Chesla (1997) acknowledged that experienced nurses were found to integrate technology and care but did not suggest how the participants demonstrated this. Chesla (1997) makes some interesting assertions in her paper, however, the participant's voice is lacking within the

reported findings leading to doubts about the reports authenticity. Furthermore it is not reported to what extent the observational data is included within the thematic analysis.

Similar inconsistencies in care were demonstrated in Almerud *et al.*'s (2008) phenomenological study of ten nurses who were interviewed about caring in a technological environment such as ICU. Almerud *et al.* (2008, p132) make some damning claims; '...it [technology] impedes any possible close encounter and sabotages the intention of developing health-inducing interpersonal relations. It also compromises the caregiver's vision and shackles action...The act skews the balance between objective distance and interpersonal closeness. It is as if technology outmanoeuvres caring insofar as the effect of medicine and machinery-management on patient care has become routine.' The authors do not make their influence on the data clear and themes are only minimally supported by participant quotations. It is therefore uncertain to what extent the themes are grounded in the participants' voice and how much might be conjecture and the author's opinion.

Other authors claim that personal care is often not prioritised due to the time consuming nature of technology in ICU. Alasad (2002) suggests that even though technology is viewed by nurses as part of everyday practice it remains demanding and time consuming. Alasad (2002) also revealed that the nurse participant viewed the technical role of the nurse as being more important than personal care and interpersonal relationships. Due to time consuming nature of technology participants revealed that sometimes they had to 'let go' of other aspects of care- the less life threatening aspects and therefore less important. Both Kongsuwan and Locsin (2011) and Almerud *et al.* (2008) acknowledge that there is a lack of time and space for existential matters in the nurses' daily routine.

Both technological competence and comforting the patients have been highlighted within the literature as fundamental components of critical care nursing. Given the inconsistencies in care described above where nurses were focussed on the technological at the cost of personal care it would appear that the notion of technological competence and comforting may make uncomfortable bed fellows. However a prevalent theme within the literature is the concept of balancing the two.

Walters (1995a) suggests that balancing recognises that caring in ICU includes both objective and subjective dimensions and that the role of the nurse is to unify the two. Within Walters' (1995a) study, participants described this as 'Caring with technology'. Participants suggested that caring was helping and as part of helping you use the tools around you (Walters 1995a). McGrath (2008) described the process of embracing technology where nurses worked in harmony with technology. McGrath (2008) likened this mode of caring practice with Heidegger's 'read-to-hand' mode of engagement where the nurse is involved in an absorbed manner and the equipment and practical activity function smoothly as they become inseparable component of the caring process. Wikström *et al.* (2007) also found that their participants described that they had integrated technology as an essential tool when performing their caring work. ICU nurse participants in Bull and Fitzgerald's (2006) study described how they take for granted the necessity of combining technology and caring.

Wilkin and Slevin (2004) identified that the essence of caring is a process of competent physical and technical action imbued with affective skills suggesting that caring involves professional knowledge, competence, skill and nursing action. However, to balance humanistic caring and technology, the participants felt that having experience and the inherent ability to prioritise care

for the individual patient was paramount (Wilkin and Slevin 2004). This finding reiterates the importance of technological competence as a function of expertise. Kongsuwan and Locsin (2011) assert that technological competency involves compassionate caring. Locsin (1999) and Little (2000) agree that true technological competence in clinical nursing practice can be understood as an expression of caring and need not always be a barrier.

Far from leading to an imbalance of care, McGrath (2008) illustrated within the theme of 'sharing the journey' that the critical nature of the technologically dependent patient brought the nurse closer to the patient. McGrath (2008) described how the nurse would empathise with the patient and their plight sharing the patient's emotions of joy, hope, and despair. The continual presence of the nurse due to the complexity of care required contributed to the shared journey. Conversely Almerud *et al.* (2008) acknowledged that technological demands resulted in a physical closeness between the nurse and the patient, however, denied that this led to a personal closeness suggesting that the nurse was only close to the patient's data, not the patient themselves.

Summary

Technology clearly plays an essential role in modern nursing practice and nursing care. It has been discussed how technology, on first consideration, may be perceived to be in direct opposition to the purported humanistic nature of nurses, nursing and care. It has been argued that the notion of the paradoxical relationship between technology and / or care is reductionist and too simplistic to accurately represent modern nursing care practices. A social constructivist approach to technology and care, which is also reflected within the existing research literature, reveals the relationship between technology and care to be far more fundamental.

Technological competence as an expression of caring, comforting and caring with technology demonstrates that far from technology and care being polarised concepts, they are inimitably entwined in nursing practice in ICU. Review of the existing evidence relating to nurses' perceptions of care delivery within a technological environment such as ICU, may help to contextualise patients experiences of receiving that care.

Much literature regarding technology and care is from either a philosophical viewpoint or only explores nurses' attitudes and experiences. The studies reviewed have predominantly adopted a qualitative approach. In addition most of these studies have been conducted in one site. Therefore the findings of these studies may not be transferable to other cultures and settings. Many of these studies seek nurses perceptions therefore there is an inherent risk that nurses offer socially desirable accounts of care rather than sharing the realities of practice. Whilst some of the studies have included an observational element, these either have not been reported at all, or their influence on the development of the themes not made explicit. A stark void within the existing evidence base is investigation of the patients' perspective of either technology or care, particularly within critical care settings such as ICU.

The following section of the literature review explores the existing evidence base relating to patients experiences of ICU with the aim of explicating the patients journey though critical illness and recovery.

Patients' Experiences

Admission to ICU following a critical illness is a very stressful experience (Mazzon *et al.* 2001; Mendelsohn and Chelluri 2003; Griffiths and Jones 2011). Patients entering ICU often present with an unexpected life threatening condition. Throughout the course of a patient's critical illness, they will require varying degrees of technological and pharmaceutical life support including respiratory, cardiovascular and renal support to preserve their physiological systems. The critical condition will last for varying amounts of time. Since the critical illness is largely unexpected often patients will not be aware of their condition until late into their stay in critical care and often not until after their discharge (Granja *et al.* 2005). There has been much research investigating patients' experiences of the acute phase of their illness as well as their long-term recovery. The following section therefore explores this literature.

Due to the nature and severity of their critical illness, administration of sedation and other pharmaceuticals, patients' memories of ICU are often fragmented and incomplete (Hull and Cuthbertson 2007; Hofhuis *et al.* 2008). Thirty to seventy per cent of ICU survivors report having clear memories (Adamson *et al.* 2004; Ringdal *et al.* 2006; Samuelson 2011). Memories in ICU vary from having vivid memories of specific events, to having hazy dream-like memories through to having no memory at all (Ringdal *et al.* 2006; Ringdal *et al.* 2009; Kiekkas *et al.* 2010; Samuelson 2011). Despite the variation in patients memory and recall there have been a number of studies that have attempted to investigate patients' experiences of their ICU stay.

The key finding of studies exploring the patient experience is that patients universally find the experience terrifying (Russell 1999; Granberg-Axell *et al.* 2001; McKinley *et al.* 2002; Rotondi *et al.* 2002; Fredriksen and Ringsberg 2007; Cypress 2011; Samuelson 2011). Patients as a result

report feelings of great anxiety (Russell 1999; Stein-Parbury and McKinley 2000; Hewitt 2002; McKinley *et al.* 2002; Roberts 2004; Roberts and Chaboyer 2004; Almerud *et al.* 2007). The incidence of anxiety in ICU has been reported to be between 30.8% (Kress *et al.* 2003) and 80% (Chlan 2003). Studies investigating the incidence of anxiety in ICU often use self-report questionnaires in survivors of ICU which may account for the variance in reported incidence. In addition, Tate *et al.* (2011) suggests that the assessment of anxiety is often inaccurate, incomplete and ineffective. Certainly there appears to be no single instrument that may quantify the complex psychological state and multiple emotions associated with anxiety of being in ICU. Tate *et al.* (2011) adopted an ethnographic approach to investigating patients' anxiety in ICU in a hope to capture both the behavioural and clinical manifestations of anxiety in patients. Their observations revealed that anxiety and agitation was commonplace. Many patients reported periods where they felt frightened and agitated. Tate *et al.*'s observations revealed that anxiety was often in response to physical and psychological stressors.

Many studies have revealed that patients in ICU endure an enormous amount of both physical and psychological stress (Kiekkas *et al.* 2010; Puntillo *et al.* 2010; Desai *et al.* 2011; Samuelson 2011). Attempts to clarify the exact stressors encountered in ICU have been made. Pang and Suen (2008) asked 60 ICU patients in China to rank stressors in ICU utilising an adapted Environmental Stressor Questionnaire (ESQ)- a tool that was originally developed by Cochran and Ganong in 1989 (Cochran and Ganong 1989). The ESQ comprises of a list of stressors that participants are asked to rank in a Likert-type scale. Participants in Pang and Suen's study described the fear of death as being the most stressful. Factors related to physical discomfort or environmental settings received significantly higher ratings. These factors included 'being restricted by tubes/lines', 'having tubes in your nose or mouth', 'being in pain', 'being stuck with

needles', 'having strange machines around you' and 'hearing the buzzers and alarms from the machinery'. Being in pain was ranked the third most stressful factor. Pang and Suen (2008) replicated an earlier study conducted by Cornock (1998) who, also using the ESQ, conducted his study in the UK. Cornock's (1998) findings varied considerably from Pang and Suen's (2008) presumably reflecting the cultural differences and twenty year gap between studies. Participants in Cornock's (1998) study revealed that patients rated 'being thirsty' as the most stressful followed in order by 'discomfort of having tubes in your nose or mouth', 'not being to communicate', 'being restricted' and 'not being able to sleep'. There are however, some limitations associated with the ESQ. Cochran and Ganong (1989) tested the original questionnaire for face and content validity by presenting it to a panel of critical care professionals and lay people. They do not however make it clear how they derived the inventory of stressors. In addition the authors do not discuss service user involvement or how patients in ICU may have contributed to the list of stressors. Elements of the original list are dated, for example the fear of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) was included, which in the late eighties was quite new and topical but may not be such an anxiety today.

Despite the limitations of the ESQ tool Cornock's and Pang and Suen's studies have revealed that there are many physical and psychological discomforts and restrictions that are a source of great stress to ICU patients. Other studies have further explored the source of physical and psychosocial stress and patients' responses to these stressors. Several themes, detailed below, have emerged from review of both medical and nursing research literature:

- Stressors in Critical Care
 - Physical stressors
 - Sleep Disturbances
 - Pain and Discomfort
 - Psychological stressors
 - Sensory Alterations/ hallucinations/ delusions
 - Impaired Communication
 - Transfer Anxiety
- Outcomes of Stressors
 - ICU delirium
 - PTSD
- Long-term Recovery and Health Related Quality of Life

Stressors in Critical Care

Physical Stressors

Critical illness alone inflicts an enormous amount of physical stress on the patient. In addition to these innate physical stressors associated with the critical illness process, there are other sources of physical stress specific to ICU which includes sleep disturbances, pain and discomfort.

Sleep Disturbances

Sleep disruption amongst ICU patients is a recognised problem (Drouot *et al.* 2008; Friese 2008). ICU patients suffer from both quantitative and qualitative sleep deprivation (Hardin 2009). Some ICU patients sleep as little as 1.7 hours per day and experience predominantly light stage 1 sleep and decreased or absent stage 2, N and REM sleep which is deeper sleep (Freedman *et al.* 2001).

In addition sleep is often severely disorganised with 50% of sleep occurring during the day (Freedman *et al.* 2001; Gabor *et al.* 2003; Hardin *et al.* 2006). According to Nelson *et al.* (2001) who interviewed patients three days after discharge from ICU, sleep deprivation was cited as the worst experience in the ICU (Nelson *et al.* 2001). In addition sleep disturbances have been reported as continuing after discharge with one study reporting that 44% patients had persistent sleep disturbances 3 months after discharge from ICU (Eddleston *et al.* 2000).

The causes of sleep deprivation within ICU are multifactorial (Drouot *et al.* 2008; Friese 2008). The general ICU environment is arguably not conducive to restorative sleep- the high level of noise, continuous artificial lighting, nursing activity, drugs, severity of illness have all been identified as potentially inhibiting normal sleep (Friese 2008; Patel *et al.* 2008). Noise levels in ICU have been found to far exceed the levels recommended by the World Health Organisation (WHO, 1980) (Patel *et al.* 2008), however, the extent to which noise contributes to sleep disturbances is widely contested in the literature. Some authors have attributed excessive noise exposure to sleep disturbances and other psycho-physiological effects (Meredith and Edworthy 1995; Christensen 2002; Monsen and Edell-Gustafsson 2004; Christensen 2005) such as the development of ICU delirium (McInroy and Edwards 2002). However, other authors have demonstrated that arousals not always correlated with periods of excessive noise (Freedman *et al.* 1999; Freedman *et al.* 2001; Frisk and Nordstrom 2003; Gabor *et al.* 2003). Celik *et al.* (2005) among others (Freedman *et al.* 1999; Frisk and Nordstrom 2003; Bourne 2004; Friese 2008) demonstrate that continuous nursing activity may be more disruptive to sleep than noise.

Other factors thought to potentially disturb sleep are disease severity (Freedman *et al.* 2001; Parthasarathy 2003; Olofsson *et al.* 2004; Fanfulla *et al.* 2011) mode of mechanical ventilation,

although this has not been found to make a significant difference (Bosma *et al.* 2007; Fanfulla *et al.* 2011), and the use of pharmacological agents such as benzodiazepines, opioids, and inotropes (catecholamines) (Bourne 2004; Hardin *et al.* 2006; Drouot *et al.* 2008; Elliott *et al.* 2011).

The exact ramifications of poor sleep quality on outcomes from critical illness is not fully understood, however the physical and psychological effects are thought to be substantial (Bonnet and Arand 2003; Franzen *et al.* 2008). There is a suggestion that sleep deprivation may affect respiratory function (Honkus 2003; Pandharipande and Ely 2006; Friese 2008) and have a detrimental effect to the cardiovascular system causing arrhythmias and exacerbate cardiac failure (Parthasarathy and Tobin 2004). The immune system is also thought to be vulnerable to sleep deprivation (Bryant *et al.* 2004; Drouot *et al.* 2008). Critically the physical effects of sleep deprivation may all delay or impede ICU patient recovery and increase length of ICU and hospital stay.

There are many behavioural consequences of sleep deprivation reported in the literature. Sleep deprivation has long been associated with the development of ICU delirium (Elliott *et al.* 2011), the development of PTSD (Franzen *et al.* 2008; Friese 2008) and depression (Elliott *et al.* 2011). The exact nature of the relationship between delirium and sleep deprivation remains to be clarified. Whilst there has been reasonably extensive research aimed at exploring this relationship, methodological limitations associated with the studies precludes the establishment of the relationship between the two phenomenon. It is not clear if sleep deprivation contributes to delirium or if delirium contributes to sleep deprivation (Trompeo *et al.* 2005; Drouot *et al.* 2008; Friese 2008; Patel *et al.* 2008). Nuttall, *et al.* (1998) carried out a retrospective survey of

137 ICU patients to determine if a difference exists in the circadian rhythm entrainment between patients with and without ICU delirium. The researchers speculated that sleep disturbances and the subsequent loss of circadian rhythm may lead to delirium however, interestingly the findings did not support this hypothesis. However, a more recent study conducted by Trompeo *et al.* (2005) prospectively studied 27 ICU patients sleep architecture using polysomnography (PSG). Trompeo and colleagues found a significant association between delirium and sleep deprivation; they found that 10 patients with delirium had a shorter REM sleep duration, and fewer REM periods, and prolonged REM latency, compared to 16 ICU patients without delirium. This study however did not establish causality between the two. Sleep deprivation was also found to be a risk factor that predicted delirium in postoperative patients (Yildizeli *et al.* 2005). However, this study was a retrospective record review, and investigators did not report how sleep deprivation was measured.

Overall, it is clear that sleep disturbances are prevalent in ICU and maybe a significant source of physical and psychological stress. The exact causes of sleep disturbances are not clear, neither are the exact ramifications of sleep deprivation. Of most significance is that sleep deprivation appears to negatively impact on patients' experiences of critical illness and intensive care, however, there appears to be no qualitative exploration of the patients experiences of sleep disturbances in ICU within the published research.

Pain and Discomfort

Pain and discomfort are significant stressors in ICU (Hewitt 2002; Kiekkas *et al.* 2010). Stein-Parbury and McKinley (2000) conducted a review of 26 studies on patients' experiences of being in ICU. They found that pain was the most common discomfort reported to staff. Interestingly in

a later empirical study, McKinley *et al.* (2002) found that participants in their qualitative study reported having no pain. In an early grounded theory study, Hall-Lord *et al.* (1994) suggested that patients in ICU endure physical, intellectual and emotional pain. Physical pain included physical discomfort, fatigue and breathing difficulties. Intellectual and emotional pain relates to the confusion, frustration and anxiety associated with the physical pain (Hall-Lord *et al.* 1994).

Pain and discomfort due to endotracheal intubation has been reported in many studies (Daffurn *et al.* 1994; Russell 1999; Adamson *et al.* 2004; van de Leur *et al.* 2004). Turner *et al.* (1990) found that 44% of patients reported tracheal suctioning as the most unpleasant experience. Many patients recall mechanical ventilation and tracheal suctioning as being deeply unpleasant (Johnson 2004; Wang *et al.* 2008). Patients' report other technologies that contributed to their physical discomfort such intravenous lines, catheters and monitoring equipment (Jablonski 1994; Johnson 2004; Celik *et al.* 2005; Cypress 2011) and were significant stressors during their ICU stay. Conversely, other authors suggest that the presence of lifesaving equipment may promote feelings of security and comfort (Hupcey and Zimmerman 2000b; McKinley *et al.* 2002). Russell (1999) performed a self reporting questionnaire on 212 patients six months after discharge, exploring patients' memories and perceptions of ICU which revealed that 76 per cent of patients reported memories of technology acknowledging its life saving capacity. However, other participants felt that technology hindered their recovery by causing them pain, discomfort and restricting their mobility.

Psychological Stressors

In addition to the psychosocial ramifications of illness and hospitalisation, such as anxiety, isolation from family, role changes, financial burdens (Rana and Upton 2009) the critically ill

patient in ICU may be subjected to additional psychological stressors which have been associated with the development of adverse psychological sequela. Key stressors identified by review of the literature include sensory alteration, impaired communication, and transfer anxiety.

Sensory Alteration

Sensory alteration, where there is a change in the quality or quantity of sensory input, may contribute to ICU delirium (Hewitt 2002). Sensory alteration occurs in several different ways in the intensive care setting: reduction in amount and variety of stimuli, excessive noise, physical and social isolation and the restriction of movement (Dyer 1995a; Granberg *et al.* 1996; Black *et al.* 1997; Gelling 1999; Ely *et al.* 2001; Hewitt 2002). Black, *et al.* (1997) argue that both sensory deprivation and overload may occur simultaneously within ICU along a continuum of sensory awareness. He describes this as sensoristrain. In his discursive paper, Dyer (1995a) equates sensory alterations to categories of psychological torture as described by Amnesty International (1974). Categories of torture include isolation, monopolisation of perception, physical debilitation, threats and displays of omnipotence all of which, Dyer argues are encountered by patients in ICU (Dyer 1995a). Dyer (1995a) described 'white sight' which is the visual monotony of ICU due to fluorescent lighting, obscured view and restriction of movement. He also referred to 'white noise' or the background hum of equipment and activity that is meaningless to the patient. Dyer (1995a) suggested that a combination of white sight and white noise may lead to sensoristrain and block the reception of meaningful stimuli. Although not based on robust research evidence but on clinical expertise and experience, Dyer's paper has been very influential and is frequently cited in other literature.

The literature suggests that excessive noise exposure may be a source of psychological stress (Baker *et al.* 1993; Meredith and Edworthy 1995; Christensen 2002; Christensen 2005) and may contribute to ICU delirium (McInroy and Edwards 2002). Excessive noise is particularly prevalent in ICU. A study conducted by McLaughlin *et al.* (1996), secretly recorded noise levels within a cardiac surgical ICU. An environmental noise meter was concealed within the clinical area and recorded noise over a 24 hour period. Permission from the clinical director and ethics committee had been sought, however, staff members working on the unit were unaware of the study. McLaughlin *et al.* (1996) found that noise levels far exceeded levels recommended by the World Health Organisation (WHO, 1980) with the highest noise of 100.9 decibels and the lowest recording of 57.5 decibels. However, the impact of this noise on patients was not explored within this study.

Christensen (2005) suggested that hospital personnel produce the majority of noise in form of conversations, daily activities and technologies inherent in the modern hospital. Christensen (2005) explored the level of knowledge that ICU nurses have on the effects of noise levels on patient in the clinical area. Christensen collected data utilising a self-administered 15 item closed-ended multiple choice questionnaire from 96 randomly selected registered ICU nurses. The results revealed that knowledge on the effects of noise exposure on individuals, patients and the work environment was poor. No significant difference was demonstrated between nurses of different grades and level of experience. Despite 50% of the respondents acknowledging that staff members are responsible for the majority of noise within ICU, they displayed a lack of awareness of how noise affects patient's recovery.

The physiological effects of noise have been well documented (Christensen 2002) and include cardiovascular stimulation (Baker *et al.* 1993) hearing loss (Thomas and Martin 2000), increased gastric secretion (Tomei *et al.* 1994) and immune suppression (Christensen 2002). The potential effect of noise on sleep has already been discussed. However, the exact impact of excess noise in critical care on patient's condition, experience and recovery is less clear. There is an assumption within the literature that excess noise may contribute to psychosocial disturbances of the critically ill. These assumptions are often based on expert opinion or anecdotal evidence, however, peer reviewed empirical evidence is lacking. Nevertheless it might be suggested that at the very least excess noise within critical care environment is an additional stressor in an already stressful environment.

Evidence suggests that touch is often impaired within ICU (Adomat 1999; Cox and Hayes 1999; Henricson *et al.* 2009). The sense of touch and bodily position may be affected by physical restraints- the restrictions of movement by invasive lines, monitoring leads, drains and catheters the restricted position change- mainly supine/ semi-supine (Cox and Hayes 1999). Chemical restraints such as sedatives and neuromuscular blocking agents may also impair touch and movement (Adomat 1999). The exact effects of inappropriate physical sensations and touch is unclear however, is suggested to contribute to sensoristrain (Adomat 1999; Cox and Hayes 1999; Henricson *et al.* 2009)

Sensory alteration is further exemplified by the frequent incidence of hallucinations and delusions reported by patients in ICU (Russell 1999; Granberg-Axell *et al.* 2001; McKinley *et al.* 2002; Roberts *et al.* 2006; Hofhuis *et al.* 2008; Samuelson 2011). Patients have commonly reported the incidence of delusional memories that include nightmares, paranoid delusions and

hallucinations (Roberts *et al.* 2007; Kiekkas *et al.* 2010). These delusional and hallucinatory memories and are often persecutory in nature and have been reported to be upsetting and frightening for the patient (Griffiths and Jones 2007; Griffiths and Jones 2011). As a result of these delusions and hallucination patients often report feeling as though they were going crazy (Griffiths and Jones 2011). The number of ICU patients who report delusional memories varies between 26% and 73% (Ringdal *et al.* 2006; Kiekkas *et al.* 2010; Samuelson 2011). The great variation may be due to the individual varied exposure to factors associated with delusional memories such as length of ICU stay, sedative and analgesic medications, severity of illness, age and ventilator support (Ringdal *et al.* 2006; Samuelson *et al.* 2007; Kiekkas *et al.* 2010; Griffiths and Jones 2011; Samuelson 2011). Increased age appears to be the greatest predictor of the occurrence of delusional memories (Ringdal *et al.* 2006). Arguably, the occurrence of delusions and hallucinations is both a source and consequence of psychological stress.

Löf *et al.* (2008) demonstrated the implications of delusional and hallucinatory memories on the recovery of the critically ill patient as often the recall of unreal experiences overshadowed the memories of factual events. The eight patients in Löf *et al.*'s qualitative study reported delusional and hallucinatory memories often dominated their thoughts and represented a heavy burden. According to Roberts and Chaboyer (2004) and further demonstrated by others (Löf *et al.* 2008; Samuelson 2011) patients may recall details of their delusional memories years after their discharge from ICU.

Impaired Communication

The majority of patients in critical care units are compromised in their ability to communicate (Happ *et al.* 2011). There are many identified barriers to communication within ICU:

endotracheal intubation, tracheostomies, sedation, muscular weakness, time-critical actions and noisy work environments are not conducive to effective communication. In addition the patient may be distressed and disorientated by the unfamiliar surroundings (Alasad 2002; Magnus and Turkington 2006; Happ *et al.* 2011). The importance of effective communication between nurses and critically ill patients is emphasized within the literature. Magnus and Turkington (2006) purport that communication may have an effect on patient outcome and quality of care delivered. In addition there are many studies that indicate that unconscious patients recollect nurses' communications and often found them reassuring (Mazzon *et al.* 2001; Lof *et al.* 2006). Equally when there is inadequate communication patients report feeling frustrated and alienated (Mazzon *et al.* 2001; Usher and Monkley 2001).

Despite the importance of effective communication between nurses and ICU patients inconsistencies in the quality of communication have been revealed in the research literature. Alasad (2002) conducted a Heideggerian phenomenological study with overt observations of communication events between nurses and patients. Twenty-eight nurses were interviewed and 240 hours of participant observations conducted. Whilst participants viewed communication with critically ill patients as an important part of nursing care the results of observed practice suggested that communication was often ineffective and inconsistent. Participants in Alasad *et al.*'s (2002) study suggested that patients' physical needs often take priority over communication. Participants also found that communication with patients is often frustrating. The study revealed that unconscious patients received less verbal communication and interaction than verbally responsive patients.

Conversely, Happ *et al.*'s (2011) descriptive observational study revealed that nurses initiated communications in 86.2% of cases and that greater than 70% of these communications were rated as successful. Happ *et al.* (2011) utilised overt video recorders to collect data which may have led to a Hawthorne effect where nurses, knowing that they were being videoed made more effort to communicate effectively. In addition the success of communications were rated using a subjective scale which may have led to bias in these results.

In addition to the frequency and method of communication, the content of communications is reported to be suboptimal. Early studies have suggested that the content of nurse-patient communications in ICU is often nurse and task orientated (Dyer 1995a; Casbolt 2002). Communications have been characterised as informative statements about physical care, yes/no questions, reassurances or commands and orientation information (Casbolt 2002; Happ *et al.* 2011). In addition communication is mostly one sided.

Effects of ineffective communication may lead to a multitude of negative emotional responses such as associated with anger, worry, and fear (Alasad and Ahmed 2005). Magnus and Turkington (2006) interviewed 8 staff and 9 patients using a structured and semi-structured approach to elicit both quantitative and qualitative perspectives of communication difficulties experienced in ICU. Patients reported feeling frustrated, lonely, terrified and powerless as a result of not being able to communicate with their carers and family. Staff too, expressed great frustration and described feelings of incompetence when they were unable to interpret their patient's attempts at communication. Ineffective communication appears to be a significant stressor to both the patient and the staff caring for them.

Assistive communication strategies such as the use of alphabet boards, picture boards or writing implements have been suggested as being able to assist with communication between patients and staff in ICU. However, Happ (2011) observed in their study that despite obvious difficulties in communication, nurses seldom utilised aids available to them. Staff participants in Magnus and Turkington's (2006) small study suggested that nurses lacked training and knowledge regarding their use. Patient participants however, valued times when staff utilised communication aids and described them as helpful. There has been no formal evaluation of communication aids within ICU within research literature.

Transfer Anxiety

Although discharge from ICU represents a positive step in terms of physical recovery, many patients exhibit high levels of anxiety at the time of transfer from ICU to a ward (Cutler and Garner 1995; McKinney and Deeny 2002; Chaboyer *et al.* 2005a; Chaboyer *et al.* 2005b; Chaboyer 2006; Chaboyer *et al.* 2008). Transfer anxiety, previously referred to as relocation stress is a transcultural phenomenon which describes the anxiety experienced when patients move from the familiar and secure environment of ICU to one that is unfamiliar (McKinney and Deeny 2002; Chaboyer *et al.* 2008). The exact number of patients exhibiting transfer anxiety has not been confirmed. A small prospective cohort study conducted by Gustad *et al.* (2008) suggested that as few as 17% of patients may exhibit signs of anxiety at the time of discharge. However, it is important to note that this study was significantly underpowered and many participants were lost to follow-up. There have been no other attempts to quantify the extent of transfer anxiety, however it is frequently highlighted within qualitative literature of being concern to patients.

Cutler and Garner (1995) offered an opinion paper which also included the results of an informal survey of 12 nurses. No ethical approval for this survey was gained. Cutler and Garner (1995) suggest factors which may give rise to transfer anxiety including reduced level of control, reduction in patient monitoring, inconsistencies in care between the ward and ICU, and little or no preparation for impending move. Cutler and Garner (1995) conjectures have, however been supported by a number of other studies that have investigated the experiences of patients transferring to the ward from ICU. McKinney and Deeny (2002) interviewed six patients and found that whilst patients recognised their transfer as an indication of their recovery they considered the lack of technological interventions and monitoring and the reduced staff-patient ratio as a reduction in care. As a result patients reported anxiety that any deterioration in their condition would go unnoticed on the ward. Chaboyer *et al.* (2008) also highlighted a lack of constant nurse presence as a significant stressor to patients discharged from ICU to the wards. Strahon and Brown (2005) in a Husserlian phenomenological study corroborated McKinney and Deeny (2002) findings. In addition Strahon and Brown (2005) described physical symptoms reported by their participants upon transfer to the ward which included sleep disturbances, fatigue, lack of muscular strength and reduced appetite. Other factors found to contribute to transfer anxiety have included lack of information (Chaboyer *et al.* 2005a; Chaboyer *et al.* 2005b) and lack of preparation (Cutler and Garner 1995; Chaboyer *et al.* 2005a)

The existing research evidence highlights the extreme nature of physical and psychological stressors confronted by patients in ICU all of which will contribute to and influence their experiences and understanding of their experiences in ICU. Although not manifestly demonstrated within the existing evidence base, conceivably, many of the stressors highlighted

may influence or be influenced by the presence of technology. Therefore exploration of the stressors endured by patients in ICU can provide a context to their experiences of technology.

Physical and psychological stressors have been explored both quantitatively utilising questionnaires and assessment tools and qualitatively using interview and focus groups to explore patient experience. Predominantly studies are single site and have, arguably by necessity, been carried out retrospectively in ICU survivors, which may limit the transferability and generalisability of the findings. The methodological limitations highlighted are not so much a criticism of the authors but revealing of the inherent difficulties, complexities associated with researching the critically ill patient. The possible outcomes and ramifications of these stressors are explored in the subsequent section and include ICU delirium, PTSD, long-term recovery and health-related quality of life.

Outcomes of Stressors

The stressors described above, have been causally implicated with adverse psychological effects in patients in ICU (Jones et al. 2007; Kiekkas et al. 2010). Anxiety, depression, ICU delirium and post-traumatic stress disorder are common in this population (Jones et al. 2001; Jones et al. 2007). ICU delirium, previously referred to as ICU syndrome or psychosis describes a range of psychosocial anomalies exhibited by ICU patients (Hewitt 2002). Characteristic signs of delirium are an acute, fluctuating, reversible disorder of attention and cognition or an altered level of consciousness (NICE 2010; Campbell *et al.* 2011; Devlin *et al.* 2011; Neziraj *et al.* 2011). Delirium may be hyperalert-hyperactive, where patients display agitation, fear, paranoia and visual and auditory hallucinations, hypoalert-hypoactive, where patients may be sluggish, lethargy and

depression, or a mixture of both (Hull and Cuthbertson 2007; Van Rompaey et al. 2008; Kiekkas et al. 2010).

The reported incidences of ICU delirium vary greatly from 11% up to 87% (Roberts *et al.* 2006; Van Rompaey *et al.* 2008; Arend and Christensen 2009; Morandi and Jackson 2011). McGuire *et al.* (2000) cites an average incidence of 40%. The discrepancy in reported incidents may be due to the variation in assessment tools utilised to diagnose delirium (Devlin *et al.* 2011; Neziraj *et al.* 2011; Reade *et al.* 2011). In addition the fluctuating nature of the condition often makes diagnosis difficult. Some studies have demonstrated a consistent rate of under diagnosis so it is likely that the true incidence may exceed 40% (Arend and Christensen 2009; Reade *et al.* 2011).

The suggested causes of delirium are many and varied and include advanced age (Marshall and Soucy 2003) increased severity of illness, hypertension (Ouimet *et al.* 2007), pharmaceutical agents such as opioids, anticholinergics, and benzodiazepines (Ouimet *et al.* 2007). Environmental stressors such as sleep disruption, noise, sensory alteration are thought to exacerbate symptoms of delirium (Christensen 2002; Christensen 2005; Akansel and Kaymakci 2008; Arend and Christensen 2009; Desai et al. 2011; Morandi and Jackson 2011) .

Delirium is associated with a greater risk of respiratory complications (Kiekkas *et al.* 2010) acute myocardial stress such as increased heart rate, blood pressure and myocardial oxygen consumption and cerebral ischaemia (Pattison 2005). All of the above may increase mortality (Van Rompaey *et al.* 2008; Morandi and Jackson 2011) and morbidity (McGuire *et al.* 2000; Roberts *et al.* 2006), reduce long-term quality of life (Van Rompaey *et al.*, 2009), prolong intensive care and hospital stay (Ely *et al.* 2001; Roberts 2004; NICE 2010).

Definitive guidelines for treatment and prevention of delirium are lacking within the literature however, Arend and Christensen (2009) suggest that efforts should focus on the minimization and/or elimination of the predisposing and precipitating factors. The National Institute for Health and Clinical Excellence (NICE) (NICE 2010) released guidelines for the diagnosis, prevention and management of delirium which also emphasise the importance early diagnosis, and interventions to prevent delirium. Although these guidelines are not specific to ICU delirium they recognise the multifactorial causes of delirium and offer suggestions for prevention that are based on both research evidence and practise expertise and experience. Suggestions include identifying patients at risk from delirium, early screening utilising Confusion Assessment Method for ICU (CAM-ICU) and minimising sleep disturbances and noise (NICE 2010).

As a consequence of traumatic experiences such as critical illness individuals may develop acute stress disorder (Corrigan *et al.* 2007). Acute stress disorder is the collection of psychological symptoms that occur after a traumatic experience (Bienvenu and Neufeld 2011). If these symptoms last more than a month then post traumatic stress disorder (PTSD) may be diagnosed (Corrigan *et al.* 2007). PTSD is characterised by three key features: intrusive, avoidant and hyperarousal symptoms. Intrusive symptoms include recurrent flashbacks and nightmares which cause the patient to re-live their traumatic experience. Hyperarousal symptoms include sleep disturbances, irritability, outbursts of anger and difficulty concentrating (Corrigan *et al.* 2007).

The prevalence of PTSD after discharge from ICU is unclear as the reported incidence of PTSD varies between 5-63% (Griffiths and Jones 2007; Jackson *et al.* 2011) with a median point of prevalence of between 19-22% (Davydow *et al.* 2009). Once again the discrepancies in reported

incidence are attributed to the difference in screening and diagnostic tools utilised (Griffiths and Jones 2007; Davydow *et al.* 2009).

Many risk factors have been associated with the development of PTSD. Girard *et al.* (2007) reported that significantly more women develop PTSD. This finding has been replicated in other studies (Cuthbertson *et al.* 2004; Rattray *et al.* 2010) however the significance of gender on the development of PTSD after critical illness remains unclear (Girard *et al.* 2007; Samuelson *et al.* 2007). There also appears to be a correlation between PTSD development and younger age (Cuthbertson *et al.* 2004; Davydow *et al.* 2009).

Other factors that influence the incidence of PTSD have been identified. Davydow *et al.* (2009) in a systematic literature review identified other predictors of PTSD- agitation in ICU, physical restraint, administration of benzodiazepine, , receipt/dose of opiates, sepsis, low serum cortisol, and duration of ventilation. In addition recall of traumatic delusions or hallucinations is associated with the development of PTSD-related Symptoms (Jones *et al.* 2001; Kiekkas *et al.* 2010). Kress *et al.* (2003) in a seminal study determined that ICU patients subjected to a daily interruption of sedatives developed fewer symptoms of PTSD (Kress *et al.* 2003). However, no significant correlation between incidence of PTSD with illness severity or the presence and duration of delirium has been found in any of these studies (Girard *et al.* 2007; Cuthbertson *et al.* 2004; Davydow *et al.* 2009).

Corrigan *et al.* (2007) carried out a Husserlian phenomenological investigation into the meaning of post-traumatic stress reactions following critical illness and intensive care treatment. Corrigan *et al.* (2007) interviewed fourteen participants. Participants expressed the need to make sense

of traumatic memories. Memories included factual and delusional accounts of events. Participants also reported that these memories haunted their everyday lives which led to distress and strain in their life situation including physical symptoms such as sweating, palpitations and sleep disturbances and psychosocial effects such as altered interactions with others and withdrawal and isolation from their loved ones (Corrigan *et al.* 2007). The authors do not make it clear within the report how they bracketed out their pre-conceptions and do not describe how they may have influenced the data and data analysis. The credibility of themes generated may therefore be cast into doubt. However, the patient voice is clearly present within the description of the themes. A positive aspect to this study is that it appears to be the sole attempt, within a large evidence base relating to PTSD and delirium that explores these phenomena from a qualitative point of view.

Delirium and PTSD have received much research attention mostly from a positivist angle which has aimed to clarify incidence, prevalence, and causal factors. Few attempts have been made to qualitatively explore the patients' experiences of delirium and PTSD. A possible explanation for this lack of research attention is that patients may only be investigated retrospectively and the innate difficulties in recruiting vulnerable patients who may have on going physical and mental health issues.

Long-term Recovery and Health Related Quality of Life

Advances in technology and medical therapies have resulted in more patients surviving critical illness. Many survivors of ICU have on going physical and psychological symptoms requiring on going rehabilitation and support in the community (Chaboyer and Elliot 2000). Adamson and Elliot (2005) noted in their systematic review of the literature, that recovery from a critical

illness may be a long process which extends well beyond hospital discharge. The long-term impact of critical illness may therefore significantly impact a patient's quality of life. There is an increasing amount of literature assessing health related quality of life (HR-QoL) after survival of a critical illness which has highlighted important information regarding the patient's perceived and actual recovery. HR-QoL is a multi-dimensional dynamic concept that includes physical, psychological, social, religious and cultural elements (Adamson and Elliot 2005).

Granja, *et al.* (2002) conducted a cohort study of 275 patients discharged from ICU over a 2 year period. Participants were interviewed 6 months after ICU discharge utilising the validated Euro Quality of Life 5 d-Dimensional (EQ-5D) questionnaire. The authors reported that 77% of all participants reported a moderate to extreme problem within one or more of the quality of life dimensions: 37% of participants reported problems with mobility, 22% reported a diminished capacity to care for oneself, 46% had problems carrying out their usual activities, 45% had on going pain and discomfort, and 54% reported symptoms of anxiety and depression. Arguably six months is a relatively short recovery period and patients still may be in their rehabilitative phase. In addition the EQ-5D is a generic tool which may not detect the peculiarities of critical illness. Nevertheless Granja *et al.*'s (2002) findings are of great concern to health care professions. Chelluri, Rotondi *et al.* (2002) conducted a prospective cohort study examining 2 month mortality and functional status of eight hundred seventeen patients who had received prolonged mechanical ventilation. Chelluri, Rotondi *et al.* (2002) reported that of the survivors, 35% were at risk for clinical depression and 78% depended on a caregiver to carry out their activities of daily living.

In a later study Granja and colleagues (2005) aimed to correlate the memories of patient's experiences of their ICU stay with their self-reported HR-QoL. Granja *et al.*(2005) conducted a prospective study of 464 patients who completed a questionnaire relating to their recollections and HR-QoL six months after discharge from ICU. Multiple and linear regression analysis demonstrated that older age, longer ICU stay, non-scheduled surgery and recurring reams were significant predictors of a worse HR-QoL. Interestingly, 41% of participants reported on going sleep difficulties, 38% had difficulties in maintaining concentration, 36% reported short term memory loss and 64% had on going pain (Granja *et al.* 2005).

Graf *et al.* (2003) conducted an prospective, observational study of health-related quality of life before, 1 month after, and 9 months after an intensive care unit stay using an established generic instrument, the Medical Outcome Survey Short Form-36 (SF-36). Two hundred forty-five patients with predominantly cardiovascular and pulmonary disorders were surveyed. Graf *et al.* (2003) suggested that quality of life after intensive care is a dynamic process with different physical and psychological functions recovering at different rates. More recently, Stricker *et al.* (2011) in a longitudinal study of quality of life after ICU admission showed that whilst mortality at nine years is high, a patient's quality of life may show improvement over time with 59% of patients reporting that their quality of life is good.

Grossman *et al.* (2000) explored the psychological adjustment of critically injured patients three months after an unexpected life-threatening accident. Grossman *et al.* (2000) examined 51 patients via a number of questionnaires and scales and face to face interviews 8-12 weeks after the accident. The authors found that restoring a sense of meaning in life was central to a patients' psychological adjustment. They also reported a significant relationship between

perceived personal capabilities and psychological well being. Significantly Grossman, *et al.* (2000) suggested that intrusive thoughts, nightmares and memories of hallucinations and delusions impaired the psychological adjustment, coping and subsequent recovery. Despite the small sample size for a study of its type the findings offer insight into the factors that influence a patient's self-reported psychological well being.

Maddox, *et al.* (2001) adopted a qualitative approach to investigating the psychological recovery following ICU. Although the researchers did not specify which qualitative methodology they adopted, they conducted semi-structured interviews with 5 patients and 4 significant others between 6-15 weeks following discharge from ICU. Maddox, *et al.* (2001) findings supported Grossman, *et al.* (2000) as participants referred to their need to make sense of their situation, a concept Maddox *et al.* described as 'moving on'. Participants also identified individual characteristics such as inner strength as influencing their recovery. Participants of Maddox *et al.*'s study also revealed that their experiences whilst in ICU affected outcomes. Intrusive and negative memories were found to impede recovery. Within their discourse, Maddox, *et al.* (2001) noted that participants did not immediately refer to their psychological well being. Frequently participants described their experiences in terms of their physical progress. In addition their physical abilities seemed to relate to their psychological well being. Patients inferred that physical and functional improvements were accompanied with an improvement in their psychological well being.

Conversely some participants in Maddox *et al.* (2001) study report positive psychological aspects of critical illness and their ICU experiences. Some participants reported feeling like a 'different person' and of having a 'positive outlook' of critical illness. Papathanassoglou and Patiraki (2003)

revealed similar findings in a phenomenological study of eight patients one year after discharge from ICU. Participants in their study described having a heightened joy of life and new found appreciation of love for their family. They also described how, after critical illness, life had an increased sense of purpose and was more meaningful. In addition some participants in their study reported spiritual and personal growth (Papathanassoglou and Patiraki 2003).

Review of the relevant literature examining patient outcomes after critical illness highlights that recovery from critical illness is a slow and inconsistent process (Chaboyer and Elliot 2000; Chaboyer 2004; Adamson and Elliot 2005) which is individual and dynamic with some dimensions of HR-QoL and psychological well being improving more quickly than others (Adamson and Elliot 2005).

Summary

Interpretation and understanding of technology may be influenced by different paradigms. Different people within different contexts may therefore have different understandings and experiences of technology. Conceivably a patients understanding and experiences of health care technologies may therefore be different to those of the healthcare professionals implementing and managing them.

The literature suggests that technology may place demands on nurses' time which may dehumanise and fragment patient care. Other literature describes 'technological caring' where nurses exhibit technological competence and balance and integrate technology with care. Within ICU, patients may be confronted with many technologies. The relationship between technology and the care delivered in ICU is complex and ill defined. Whilst nurses' perceptions

of delivering care to patients in the technological environment of ICU have been well documented, patients' experiences have been neglected.

Patients in ICU undergo a number of extreme physical and psychological stressors that may result in the development of varying degrees of psychological and emotional disturbances from anxiety and depressive disorders to ICU delirium. It is also evident that the psychological recovery of patients in ICU is slow and often may lead to long-term reductions in health related quality of life as well as the development of post-traumatic stress disorders. Investigation into the stressors encountered in ICU and the subsequent development of psychological disturbance has mostly been conducted utilising a quantitative methodology. Relatively, there are few qualitative investigations into patients' experiences of ICU. Some qualitative studies have investigated the general lived experience of ICU (Hupcey and Zimmerman 2000b; Hofhuis et al. 2008; Cypress 2011). Others have looked at specific elements of ICU such as experiences of therapeutic touch (Cox and Hayes 1999; Henricson et al. 2009) mechanical ventilation (Jablonski 1994; Wang et al. 2008) or communication (Magnus and Turkington 2006). However, the majority of ICU related qualitative research has focussed on patients' experiences of phenomenon encountered after ICU discharge such as transfer anxiety (McKinney and Deeny 2002; Strahan and Brown 2005; Chaboyer et al. 2005a), PTSD (Corrigan et al. 2007), follow-up clinic (Engstrom et al. 2008), patient diaries (Egerod and Bagger 2010a), and patient memories and dreams (Adamson et al. 2004; Roberts and Chaboyer 2004; Samuelson 2011). Whilst these all of these studies have contributed to an understanding patients experiences of critical illness, care in ICU and recovery they are not exhaustive. In particular investigation of patients' experiences whilst in ICU is particularly limited.

This study therefore acknowledges that patients' experiences and understanding of technology may differ to those of healthcare professionals and investigates their experiences of technology whilst in ICU serving to address some limitations of the existing evidence base.

Chapter 3: Research Methodology

Introduction

The nature of research based knowledge depends on the philosophical stance or paradigm adopted to generate the knowledge (Annells 1999). Thus it is important for the researcher to have an understanding of the research methodologies' philosophical assumptions and the implications they may have on the knowledge generated as this will influence its relevance to health care practice (Van der Zalm and Bergum 2000). Choice of methodology should therefore be guided by the nature of knowledge required to answer the research question and meet the research objectives (Mackey 2005). The following chapter aims to discuss different research paradigms in relation to the identified research question and objectives. In doing so, the extent to which philosophical principles may be utilised within the more pragmatic concerns of research will be discussed. Specific research methodologies will then be discussed in relation to the chosen research topic. Review and analysis of the existing evidence base clarified the key research question and research objectives as follows:

Research Question:

What are patients' experiences of technology in adult intensive care?

Research Objectives:

- To explore patients' perceptions of receiving care in a technological environment
- To explore patients' perceptions of how technology has influenced their experience of care

Review of the literature relating to technology, care and intensive care revealed that research endeavours have predominately explored the perspectives of nurses. In addition it became apparent that whilst there were some qualitative investigations into patients experiences of aspects of care in ICU these were relatively sparse. Qualitative investigations have focussed on experiences of ventilation and weaning, transfer from ICU, recovery from critical illness, memories, and the use of diaries. Many elements of the patients' experiences and psychosocial ramifications have been approached from a positivist or quantitative perspective; for example sleep has been evaluated by polysomnographic measurement, incidence of anxiety and depression has been assessed using Hospital Anxiety and Depression Scale or Impact of Trauma Scale, incidence of delirium and PTSD measured using a variety of screening tools, perceptions of stressors using Likert type scales, health-related quality of life using the SF-36 or EQ-5D. Whilst this research has led to a good understanding of the incidence of physical and psychological sequelae associated with critical illness and identified some potential causative factors, this has not adequately explained what it is like to be a patient in ICU. Since so little is known about this area and patients' views are relatively under explored, an inductive, rather than deductive, approach was deemed appropriate. A survey or questionnaire may presume factors that are of significance to the patient in intensive care and limit patients' expression of their experiences. Furthermore a survey may not be sensitive to the wide range of patients' experiences of technology and intensive care. In light of the limitations highlighted above, a positivist research methodology was not selected for this research. The relative paucity of qualitative evidence suggests that there are challenges in researching patients' experiences of critical illness and being cared for in ICU. For this reason an inductive, naturalistic methodology which seeks to explore individuals' experiences within a natural, social context was chosen for this study.

Naturalism is philosophically underpinned by the notion that human beings live in their own worlds and create their own understandings of reality (Gerrish and Lacey 2010). There is not one verifiable truth that can be discovered, but multiple truths reflecting the subjective experience of each individual. The naturalistic paradigm has evolved into subsidiary philosophies such as interpretivism, constructivism both of which have their own sub-branches. As such a variety of what are commonly referred to as 'qualitative' or 'naturalistic' research approaches have evolved that are regularly adopted within health care research. Starks and Trinidad (2007) argue that qualitative approaches have both differences and similarities. Qualitative approaches such as phenomenology, discourse analysis, grounded theory and ethnography are the products of different intellectual traditions, however, their co-evolution in history means that the boundaries between them are sometimes porous (Davies and Dodd 2002; Starks and Trinidad 2007).

Various naturalistic methodologies were considered for the current research, including grounded theory, ethnography, discourse analysis and phenomenology. Grounded theory aims to develop explanatory theories of basic social processes studied in the environment within which they take place (Starks and Trinidad 2007). Grounded theory was not chosen as the aim of this study was to develop an in depth understanding of individual's experiences rather than generating a general theory. Similarly ethnography was discounted since ethnography aims to explore cultural interpretations within a given context rather than the individual experience (Weaver and Olson 2006; Dew 2007). Discourse analysis examines how language is utilised by individuals to negotiate and construct knowledge (Starks and Trinidad 2007). Since discourse analysis emphasises the importance of *how* experiences are expressed (Dew 2007; Starks and Trinidad 2007) rather than examining the meaning and understanding of experiences, this

methodology would not optimally address the research aims. A phenomenological approach to the study was deemed the most appropriate methodology to generate data reflective of the research aims and objectives since phenomenology is concerned with developing an in depth understanding of individual's experiences (Dowling 2007; Sinuff *et al.* 2007). The following section discusses the key philosophical tenets associated with phenomenology. Different phenomenological schools will be discussed and the strengths and limitations of each approach highlighted. Heideggerian phenomenology will be presented as the most appropriate methodology to adopt in this study.

Phenomenology

Phenomenology, as a methodological approach to inquiry, has become a dominant means in the pursuit of knowledge development in the human sciences (Barkway 2001; Dowling 2007). Phenomenology emerged at the end of the nineteenth century in response to a crisis in philosophy where positivism was unable to answer the questions being asked of human sciences (Sadala and Adorno 2002). Although the early use of the term phenomenology is evident within the history of philosophy, Edmund Gustav Albrecht Husserl (1859-1939), a German philosopher and mathematician, is considered the founder of contemporary phenomenology (Draucker 1999). Husserl's work was influenced by many notable philosophers such as Franz Brentano, Carl Stumpf, Rene Descartes, Gottlob Frege and Immanuel Kant (Johnson 2000). Husserl's philosophy was subsequently developed by his student Martin Heidegger (1889-1976) and later existential thinkers such as Maurice Merleau Ponty, Hans-Georg Gadamer and Jean-Paul Sartre (McConnell-Henry *et al.* 2009).

Phenomenology is affiliated with a naturalistic paradigm, which is characterised by the notion that human beings live in their own world creating their own knowledge and understanding of reality (McNamara 2005). Reality is comprehended through embodied experience and the meaning of an experience may be captured by the analysis and examination of individual experiences (Starks and Trinidad 2007). This is in contrast to the positivist world view, which has its roots in natural sciences and presumes knowledge to be an objective truth, which may be extracted from the empirical world through systematic and objective observation and measurement (Johnson 2000). Researchers have looked to phenomenology as it may provide understanding of a person's reality and experience whilst valuing individuals. However the philosophy of phenomenology does not constitute a research method rather a research endeavour may be informed by phenomenology and refer to a set of disciplinary understandings which inform its scope, focus and direction (Todres and Wheeler 2001).

The application of phenomenology to nursing research has been the subject of much discussion and debate amongst nursing scholars. Controversy has arisen not from the principles of adaptation but from its interpretation or misinterpretation as applied to research methodology (Crotty 1996; Paley 1998). Mackey (2005) suggests that the literature reflects a concern with the nurse researchers inconsistent adoption of phenomenological research methods and varying interpretations of the philosophical foundations. Spiegelberg (1982) commented that there as many styles of phenomenology as there are phenomenologists. Arguably the variable interpretation of phenomenology reflects the tenets of the philosophy itself and highlights the complex and dynamic nature of both phenomenology and nursing research. The philosophy has been reinterpreted and comprises of several related but not homogenous, parallel streams stemming from the work of Husserl (Dowling 2007). In order to characterise phenomenology, as

a research approach it is necessary to explore the origins and developments of the philosophy. The central tenets fundamental to phenomenology including the ontological and epistemological views further clarify phenomenology as an approach relevant to nursing research. The following section aims to explore the key tenets in more detail.

Husserlian Phenomenology

Husserl's philosophy was primarily concerned with consciousness and its structures. Husserl sought to explain the way in which phenomena appear to us (Paley 1997). In that sense Husserl's concern is frequently described as epistemological. In order to explain our ways of knowing, Husserl developed many important concepts central to phenomenology based on the works of his teachers, the philosophers Franz Brentano and Carl Stumpf (Dowling 2007). The following section discusses these key concepts with the aim of clarifying how these may be interpreted and adapted into a research method.

Intentionality

Influenced by Brentano (1838-1917) Husserl developed the notion of intentionality as the fundamental concept for understanding (Husserl 1975; Lopez and Willis 2004). Brentano suggested that every mental phenomenon (that is, every psychological act) has intent, and is directed at an object which he described as the intentional object (Dowling 2007). Paley (1997) highlights that Husserl utilizes the term 'object' as a generic term which can refer to anything such as facts, concepts, pains, dreams, essences, and data. In other words consciousness is always directed at something, thinking always involves thinking about something (Rapport and Wainwright 2006). Implicitly intentionality means that there is no consciousness without the world, nor is there a world without consciousness (Husserl 1975; Sadala and Adorno 2002).

The concept of intentionality implies that consciousness forms the basis of all understanding and that all perceptions have meaning. Through the intentionality of consciousness all actions, gestures, habits and human actions have meaning (Husserl 1975). The purpose of Husserlian phenomenology is to describe the internal experience of being conscious of phenomena (Draucker 1999). Husserl wanted to bring to light the ultimate structures of the consciousness. With the underlying premise of intentionality, Husserl's goals are strongly epistemological (Dowling 2007). Epistemology refers to the nature of knowledge and understanding of reality (Koch 1999). Husserl's fundamental epistemological assumption is that experience as perceived by human consciousness has value and should be an object of scientific study (Lopez and Willis 2004). Husserl therefore regarded experience as the fundamental source of knowledge (Husserl 1975; Dowling 2007).

Life world and Essences

Husserl projected the concept of *lebenswelt* (Husserl 1975) which has been translated as life-world (Koch 1995; McConnell-Henry *et al.* 2009). Husserl argues that the life-world is the world 'as lived' prior to reflective representation, theoretical analysis or interpretation (Dowling 2007). The idea of life-world links a phenomenon and being in an inseparable way: a phenomenon only exists when there is a subject who experiences the phenomenon (Sadala and Adorno 2002). Presumably, Husserl's answer to the age old question, 'If a tree falls in a forest with nobody there to hear it, does it make a noise?' would be no.

Husserl contends that experiential happenings cannot be adequately described behaviourally from an external perspective as experiences irreducibly include understandings, feelings, and perceived relationships (Johnson 2000). Life-world therefore suggests that the lived experience

is more complex than the known. An underlying assumption of a Husserlian approach to the study of human consciousness is that there are features to any lived experience or life-world that are common to all persons who have the experience (Lopez and Willis 2004). Husserl referred to these as eidetic structures or universal essences (Hallet 1995). Eidetic structures, universal essences and essences are used interchangeably in the literature. For the purpose of this paper, I will subsequently refer to essences. In order to access these essences, Husserl believed you had to suspend preconceptions as much as possible in order that descriptions of the essences can reveal the complexities of the life world.

Phenomenological Reduction

For Husserl the aim of phenomenology is the rigorous and unbiased study of the essence of phenomena as they appear in the life-world to understand human consciousness and experience (Sadala and Adorno 2002). The natural attitude is engaged and absorbed which may conceal the extraordinary in the ordinary, the strange in the commonplace, the hidden in the obvious (McNamara 2005). The natural attitude and the culturally and socially derived understandings with which we operate may therefore mask the essence (McNamara 2005). In order to hold the natural attitude, including subjective perspectives and theoretical constructs, in abeyance and facilitate the essence of the phenomena to emerge, Husserl devised phenomenological reduction (Dowling 2007).

The concept of phenomenological reduction is also referred to in the literature as *epoché*, reduction or bracketing (Todres and Wheeler 2001; de Witt and Ploeg 2006; Delmar 2006; Rapport and Wainwright 2006; Dowling 2007; Starks and Trinidad 2007). It is not clear from the authors' use of these terminologies whether they are directly interchangeable or whether there

are subtle nuances that distinguish one from the other. However, Dowling (2007) describes *epoché* as a Greek word meaning to refrain from judgement or stay away from the everyday, commonplace way of perceiving things. Husserl picked up the notion of phenomenological *epoché* as a means of revealing the essences of the life-world (Draucker 1999). For Husserl *epoché* represents the theoretical moment where all belief in the existence of the real world, and consequently all action in the real world, is suspended or 'bracketed' (Husserl 1975; Rapport and Wainwright 2006).

Reduction to the fundamental essences requires the phenomenologist to examine the essence of a mental object with the intention of drawing out the absolutely necessary and invariable components that make the mental object what it is (McNamara 2005). The concept of *epoché* or bracketing can be most easily understood as systematically peeling away the symbolic meaning of a phenomenon, like layers of an onion until only the thing-in-itself remains. Therefore, one's subjective perception of the bracketed phenomenon is the truest form of experience one can have in perceiving it (Hamill 2010).

According to Husserl, phenomenological reduction or *epoché* allows us to explore phenomena exactly as they are experienced (Rapport and Wainwright 2006; Earle 2010). Phenomenological reduction, in essence disregards extraneous features to allow the clear perception of the universal essences (Hallet 1995; Hamill 2010).

Implications for research

The key tenets of Husserlian phenomenology have several key implications for research. Primarily intentionality recognises that human experiences are sources of knowledge which therefore places the person at the centre of all inquiry (Earle 2010). Subjective human

experiences are therefore the source of data. Life-world infers that the experience and the person are inseparable. This inseparability means that phenomena cannot be observed, measured or noticed behaviourally. In order to access phenomena within its full context, the researcher is therefore obliged to access the participant's life world. Data collection conducted within the Husserlian tradition typically utilises open interviews as a means of accessing a participants experiences (Hamill 2010).

Since, according to Husserl, an essence of a phenomenon may only be understood after a process of phenomenological reduction or bracketing, the Husserlian researcher is fundamentally obliged to suspend all judgements, preconceptions and every assumption normally made. Dowling (2007, Page 132) suggests that Husserlian phenomenologists must 'attempt to meet the phenomenon as free and as unprejudiced as possible in order that the phenomenon present itself as free and as unprejudiced way as possible so that it can be precisely described and understood'.

The issue of bracketing is subject to debate in the health research community. Bracketing within health research literature frequently refers to the process of the researcher examining their prejudices and preconceptions, putting them to one side in order to enable a clear view of the participant's experiences (Dowling 2007; Earle 2010; Hamill 2010). Paley (1997), however, suggests that true bracketing of pre-conceptions is impossible to achieve as, to suspend *all* preconceptions, the researcher would have to remove themselves from the social world. In doing so the life-world would then become inaccessible to the researcher because any judgements made are among those which, after bracketing, they are barred from using to inform their description of the phenomenon in question (Paley 1997). McNamara (2005),

however, suggests that the notion of bracketing means that rather than bracketing the natural attitude, researchers typically bracket in order to remain faithful to the participant's experiences but not to the phenomena itself. Paley (1997) criticises research for misinterpreting fundamental terminology associated with Husserlian phenomenology, which he suggests leads to inconsistencies and incoherencies within health care research.

Husserlian phenomenology may complement the research aims of this study as it places the patient and their individual experiences of technology in ICU at the centre of the study, acknowledging the patient participant as the source of knowledge. However, there are also limitations associated with Husserlian phenomenology. As a critical care nurse, I acknowledge the difficulty/ impossibility of bracketing my preconceptions and prejudices associated with a patient's experience of technology within critical care. In addition I believe the contextual influences of a patient's experience of technology including my own preconceptions will enrich the potential data. Adopting a Husserlian phenomenological approach could preclude incorporation of a lot of the complexities of critical care. Assuming that bracketing and reduction into essences is possible, the complex care environment, with physical, social and psychological complexities would not be acknowledged within the research data. Arguably by removing this contextual understanding the phenomenon or essence of the phenomenon would lose meaning rather than gaining it. As such a Heideggerian approach will now be considered.

Heideggerian Phenomenology

Martin Heidegger (1889-1976) was a student of Husserl (Draucker 1999). Like Husserl, Heidegger purported that phenomenology is concerned with human experience as it is lived (Dowling 2007). Heidegger differs from Husserl's notions of intentionality and universal essences and

instead emphasises understanding of being (Dowling 2007). Heidegger's philosophy of understanding is founded on the ontological view that lived experience is a constructivist process. Constructivism asserts that reality is a mental construction created by an individual within a social, psychological and historical context (Annells 1999). Reality is, therefore not one verifiable truth or essence that can be discovered, but is a multiple of truths, ungoverned by any natural laws, which reflects the subjective experience of individuals (Koch 1999). Since reality, according to constructivism, is a socially created entity, then knowledge and understanding of reality (epistemology) is also an individual social construct (Smythe *et al.* 2008; Earle 2010). Within constructivism, the ontology and epistemology merge because the knower is inseparable from what may be known within the overall construct of a particular reality. Humans create their own understanding of knowledge, within a particular social context; therefore, knowledge is embedded within a historical, social, and cultural setting (Van der Zalm and Bergum 2000).

Counterpoint to Husserl's epistemological emphasis, Heidegger's philosophical concerns were ontological as he aimed for understanding of being itself (Mackey 2005). Heidegger considered that inquiry must seek answers to the primordial ontological question 'What does it mean to be?' before looking to examine what can be known about existence, truth and the nature of reality (Heidegger 1962; Mackey 2005). Heideggerian phenomenology is holistic in perspective and aims to gain an understanding of the totality of the participant's lived experience (Todres and Wheeler 2001; McKinney and Deeny 2002).

There are a number of key precepts that underpin Heideggerian phenomenology which further clarify this philosophy as a research methodology:

Being-in-the-world

There are two predominant ontological standpoints, that of realism and relativism. Realism assumes entities, and knowledge about these entities, is 'out there' waiting to be discovered in their essence (Weaver and Olsen 2006). Relativism presumes reality to be projected upon an entity by a perceiving subject (Johnson 2000). Both ontological perspectives argue about the source of an Archimedean point of certainty (Johnson 2000). The Archimedean point of certainty is a hypothetical vantage point from which an observer can objectively perceive the subject of inquiry; the ideal point of certainty being a point where the subject is removed from the object so that one could see the object in relation to all other things but still remain independent of them. The expression derives from Archimedes who claimed that given a solid point on which to stand and a long enough lever he could lift the Earth off its foundations.

Despite being opposing views, the notions of realism and relativism are united in the assumption that objects or entities are separated from the knower. Heidegger was revolutionary in that he rejected the need for a Cartesian transcendental standpoint, or Archimedean point of certainty, on which to ground knowledge and experience (Johnson 2000). Heidegger rejected the notion that humans are observing subjects separated from the world of objects about which we try and gain knowledge; rather we are beings inseparable from an already existing world. Heidegger considered the object and subject to be inseparable and he represented this in his use of the term *dasein* (Heidegger 1962). *Dasein* is most commonly translated as being-in-the-world (McNamara 2005).

Being-in the-world suggests that human beings cannot exist except in the framework of an encompassing world (Mackey 2005). People are not fixed substances in a fixed world and the world does not constitute or determine the human being (Todres and Wheeler 2001). Heidegger

claimed that we are already integral and inseparable elements of an external reality and we are already in a state of being-in-the-world (Heidegger 1962; Rapport and Wainwright 2006). Heidegger rejected Husserl's notion of intentionality which emphasised that the state of mind is directed towards objects of consciousness (Rapport and Wainwright 2006). Heidegger stated that our relationships with things is not as subjects related to objects but as beings whose knowing is prior to conscious knowing (McNamara 2005). In other words Heidegger suggests that we know the world before we are consciously aware that we do (Rapport and Wainwright 2006).

The concept of being-in-the-world is not a spatial relationship describing the physical sense of living in the world but conveys a metaphysical existence which allows us to be open to and inseparable from the relationships between ourselves and that which is going on around us (Maggs-Rapport 2001). Heidegger emphasized that the world cannot be considered a thing. The world is the totality of entities, each of which exists in an interwoven matrix of relationships (Johnson 2000). Being-in-the-world, therefore, describes the unified and integrated relationship between humans and the entities that they encounter (Heidegger 1962). Being-in-the-world infers that humans have a practical engagement with the world that surrounds them (Draucker 1999). Heidegger viewed the world of humans as one of practical involvement (Johnson 2000). People, therefore, encounter entities or phenomena with engagement (Heidegger 1962). The meanings of entities are interpreted in relation to this engagement or purpose. An example of this practical involvement and engagement with the world was discussed in the previous chapter when discussing Heidegger's thoughts about human's engagement and relationship with technology.

Heideggerian research seeks to uncover what it means to be a person being-in-the-world. As much as a participant is being-in-the-world so too is the researcher. The participant's experiences and interpretations of being-in-the-world may therefore only be interpreted and understood by another being-in-the-world (Lowes and Prowse 2001). In contrast to a Husserlian approach, the Heideggerian researcher does not attempt to gain an objective or value-free understanding of a phenomenon but adopts an emic position in the research process. The researcher therefore is an active participant in the research rather than a passive recipient of knowledge (McConnell-Henry *et al.* 2009).

Fore-structures

Heidegger believes that meaning or knowledge arises, not from consciousness like Husserl, but from the essential finitude of being human (Johnson 2000). Heidegger argues that humans do not consciously perceive things but interpret them within the context of our being-in-the-world. Meaning or reality is therefore always within the social, cultural and historical context of the interpreting subject (Johnson 2000). The social, cultural and historical context of a person being-in-the-world gives rise to fore-structures (Earle 2010). Fore-structure is what is understood or known in advance of interpretation (Mackey 2005). Humans in the process of interpreting phenomena therefore have background expectations and frames of meaning that arise from their fore-structures. Some authors refer to these fore-structures as pre-understandings or pre-conceptions (Johnson 2000; Mackey 2005).

Researchers subscribing to Heideggerian philosophy acknowledge that they can only interpret a phenomenon according to their fore-structures- in other words their own beliefs, experiences and preconceptions (Todres and Wheeler 2001). The key distinction between Husserlian and Heideggerian philosophy is that Heidegger suggests that pre-suppositions cannot be suspended

or bracketed because they fundamentally constitute meaning. To ignore fore-structures would also ignore the fundamental contextualised nature of being-in-the-world and of human understanding (Johnson 2000). Experiences can therefore only be understood in terms of one's background, historicity and the social context of the experience (Draucker 1999). Heidegger suggests that we are always already in the world in association with others not as observing beings but as beings inseparable from that which is observed (Rapport and Wainwright 2006).

Heidegger suggested the notion of the hermeneutic circle whereby there is reciprocal activity between forestructures and understanding (Earle 2010). The researcher is therefore obliged to examine and explicate their forestructures as essential to the co-construction of understanding. Reflection on forestructures or preconceptions is an integral part of the interpretive process (Flood 2010). Unlike Husserlian phenomenology, forestructures that the Heideggerian researcher brings to the research are examined and explicated rather than suspended or bracketed (Draucker 1999; Johnson 2000; Flood 2010).

Language

Heidegger believed that language was a key constituent of being-in-the-world (Koch 1995). Heidegger identified language as a method of identifying and understanding phenomena since it is through language and speech that our being-in-the-world is both manifested and understood (Maggs-Rapport 2001). Therefore, eliciting stories of experience through language enables the significance and understanding of experiences to be revealed (Whitehead 2004). Researchers may therefore construct meaning and understanding that is embedded in narratives through the study and evaluation of language and texts (hermeneutics) (Finch 2004; Flood 2010). However,

Heidegger highlighted that language may be restrictive by limiting our expression of understanding of the world (Debesay *et al.* 2008).

The centrality of language in the understanding and expression of being-in-the-world has an influence on research methods that may be adopted within a Heideggerian phenomenological paradigm. Data generation is usually achieved by interview between researcher and participant (Lowse and Prowse 2001). Through the interview process understandings of both the participant and researcher will be revealed through the use of language in a co-constructive process (Koch 1999). Koch (1999, Page 176) suggested that the data generated by interview with the participant may then be fused with the experiences of the researcher and placed within a context. This process is known as the co-construction of data (Draucker 1999). Constructivist ontology has specific relevance to the chosen area of research as the intention of the study is to elucidate patients' understanding of technology within the social context of critical care. An authentic and rich account of the lived experience may only be achieved if the assumptions of multiple realities are appreciated. Enquiry into the meaning of technology also concurs with constructivist epistemology. Meaning and understanding is inherently subjective and contextual. However, it is this subjectivity of the experience of technology within the social context of critical care that might produce the most enriching and enlightening accounts of technology and care.

Temporality and Space

Heidegger suggests that understanding through interpretation must be grounded in a consideration of time (Mackey 2005). Heidegger conceives time as 'the horizon for all understanding of Being and for any way of interpreting it' (Mulhall 2005, Page 156). In essence,

as the most fundamental structures of human existence, all understandings and meanings are founded in time (Johnson 2000). Therefore Heidegger considered people to be temporally situated in-the-world. Temporality refers to the dynamic structure of being human, for whom entities may have meaning (Johnson 2000).

Temporality allows past, present, and future to be experienced as unity such that what is experienced in the present is coherent with past experiences and what is expected to be experienced in the future (Mackey 2005). Heidegger described this as a state of 'becoming' (Johnson 2000). Because the essence of time is orientated towards the future, people are always constituted by their movements into the varied possibilities of what they could become. Temporality and the state of 'becoming' allow historical understanding, which may incorporate cultural, social and experiential influences that are embodied in our 'being' (Heidegger 1962; Mulhall 2005).

Heidegger asserts that present things get their meaning out of future purpose. Although there are many possibilities that may give particular meaning to our lives, Heidegger suggests that death is the most meaningful-giving possibility (Johnson 2000). Heidegger described death as being the most fundamental ontology. For Heidegger, death is what makes being-in-the-world individual as it is non-relational: nobody can take death away from an individual, or die in somebody else's place, and we cannot understand our own death through the death of another (Jasper 1994). Death is determinate in its inevitability, however is indeterminate in its nature: one never knows exactly when or how it is going to come. However, Heidegger asserts that the indeterminacy of death does not put it in some distant, futuristic 'not-yet' way; the

understanding of the inevitability of one's own death is already part of being-in-the-world (Johnson 2000).

Being-in-the world means existence is not only temporal but spatial (Mackey 2005). Heidegger describes spatial situatedness as 'the there'. A person may bring something close to them or experience it as remote (Mulhall 2005). This does not necessarily refer to actual measurable distance but about what matters or is of concern to the individual. So what is brought to the foreground and what is relegated to the background depends on the unique situatedness of the individual in-the-world (Mackey 2005). Since temporality and space is so fundamental to being-in-the-world and our understanding these notions will influence the interpretation and analysis of the co-constructed data generated by the researcher and the researched.

Implications for Research

The primary aim of adopting Heideggerian phenomenology as a research approach is to increase understanding of phenomena as experienced in life (Draucker 1999). The primary research question of this study is 'What are patients' experiences of technology in adult intensive care?' Adopting a Heideggerian phenomenological approach to study will provide an in depth, patient centred understanding of technology as experienced by patients in intensive care. This methodology acknowledges the individual nature of being-in-the-world and the inseparability of the patients experiences of technology from the context within which their experiences occur. This aims to generate a very rich and authentic understanding of patients' experiences whilst acknowledging the uniqueness and diversity of experiences. In addition Heideggerian phenomenology allows for the co-construction of understanding acknowledging forestructures of both the researcher and the researched adding to the authenticity and richness of

understanding. Heideggerian phenomenological data aims to offer a holistic understanding which values the human and interpersonal aspects of the lived experience which complements the research aims and objectives of this study.

Phenomenology whilst being presented as an ideal methodology for the enquiry into the lived experience is not without its challenges. Phenomenology emphasizes the existence of multiple realities that are context dependent. The researcher is challenged to focus on the phenomena of interest whilst acknowledging other phenomena intrinsically associated with the given context. This is especially relevant to the research topic. The context of the intensive care environment and the experience of critical illness may have a huge impact on the patient's lived experience of technology. Teasing out specific understandings of technology which are embedded within the overall context of intensive care and critical illness may therefore be a challenge. In addition the researcher must clarify whether it is the nature of the phenomena that is under investigation, or the experience of the phenomena. The actual definition will have implications on the nature of data collected. This study focuses on the experience of technologies in relation to their care rather than technology in isolation. Arguably, according to Heidegger's ontology, the phenomena, and the experience of the phenomena are inseparable. The researchers challenge is, therefore, to co-construct meaning and understanding of the experience through shared narrative whilst acknowledging the inseparability of the phenomena itself.

The Heideggerian researcher, during the co-construction of understanding seeks the appropriate balance of contribution from the researcher and the participant in the co-construction of knowledge to ensure an authentic account of the phenomena. In acknowledging their subjectivity, researchers, during the process of co-construction, must therefore take care

to present actual experiences rather than anticipated ones. Appropriate representation of participants experiences also relies upon the researcher's artistic-literary capability and integrity when reflecting on the data and writing up and presenting a coherent narrative (Gerrish and Lacey 2010).

Successful phenomenological studies depend on full and rich verbal accounts of understandings and experiences. This therefore relies on participants' ability to articulate their understandings and experiences. This is a particular challenge for this study as the study population are by their nature vulnerable, likely to have on-going physical and psychological problems and may have impaired memory of their stay in ICU.

The results of phenomenological inquiry depict and describe many possible experiences. Therefore all phenomenological descriptions may be challenged by another. As a result a full explanation of the world with established laws and causal relationships is not possible. More likely, phenomenological studies will infer concepts which may in time contribute to theory development.

Summary

The research aims and objectives have been clarified and justified in light of the highlighted deficiencies of the existing evidence base. A naturalistic paradigm has been presented as the most appropriate approach to this research endeavour. A number of naturalistic methodologies were considered, however, phenomenology was the eventual approach deemed to be most closely aligned to the research aims. Heideggerian phenomenology is discussed in detail and has been chosen over approaches informed by Husserl. The key advantages of this approach are its

patient centred, holistic approach that acknowledges and embraces the contextual and interpersonal elements of the phenomenon in question.

The following chapter explores how the philosophical tenets associated with Heideggerian phenomenology may be reconciled into research methods.

Chapter 4: Research Methods

Introduction

Heideggerian phenomenology is primarily a philosophy. Heidegger's intention was not to develop a method for research; nevertheless, the philosophical framework carries implications for the research methods employed. Heideggerian phenomenology is such that the key tenets discourage the construction of a predetermined set of fixed procedures and techniques that would ordinarily govern a research project. Van Manen (1990) asserts that there is a definite 'way' guided by a Heideggerian framework. Significantly Heidegger described phenomenological reflection as following certain 'paths' towards a 'clearing' where something could be shown and revealed (Van Manen 1990 p29).

Smythe *et al.* (2008) suggest that there is a temptation to accept the philosophical underpinnings of methodology and then move swiftly into a neat, pre-ordained orderly method. However, the 'way' or method must embrace Heidegger's understanding of *dasein* as being there, being open, and being-in-the-world. The notion of an individual being-in-the-world each with a unique experience and understanding of being means that Heidegger's philosophy may be enacted differently by each one of us. Smythe *et al.* (2008) suggest that an attempt to pin down a pre-ordained orderly method may lose the salient nature of phenomenological inquiry.

The pragmatics of research require there to be a recognisable approach (Robertson-Malt 1999). The following section discusses how the phenomenology as a philosophy may be translated into a research method and the inherent problems and limitations in doing so. I initially present a brief overview of the scholarly debate instigated by Michael Crotty's (1996) controversial

critique of phenomenological nursing research. I will present some scholars' responses to Crotty's arguments and finally explain the chosen stance adopted for this research project. Finally I will present discussions of the selected research methods illustrating the delicate balance between consistency with philosophical tenets and research governance.

From Methodology to Method: An Impossible Task?

The ease at which a method may be extrapolated from Heideggerian phenomenological philosophy has been widely debated in the literature and has at times evoked controversial debate. Van Manen (1990, Page 30) suggests that whilst Heideggerian philosophy does not offer direct guidelines it offers 'tradition, a body of knowledge, insights and a history of phenomenological researchers which constitutes a source and methodological ground for present research practices'. Smythe, *et al.* (2008) suggested that phenomenological researchers should never plan ahead but should submerge themselves within the experience of the research and confront possibilities and make choices drawing from who one is and is becoming. Whilst this suggestion is consistent with Heideggerian thought it is not enough to satisfy the demands of research governance for transparent, ethical and robust research methods.

It is this variation in interpretation of both Heideggerian philosophy and how that may be reconciled into a research method that has been the centre of much controversy and debate. The key criticisms of nursing research are that key philosophical notions are detached from phenomenological methods. The foremost instigator of this suggestion was Michael Crotty in his controversial book entitled 'Phenomenology and Nursing Research', published in 1996. Crotty (1996) reviewed 30 nurse research articles and concluded that 'much of the research carried out by nurses, particularly North American nurses, is not *pure* phenomenology' (Barkway 2001, Page

191). Crotty (1996) distinguished between 'pure' European phenomenology and what he described as 'new' phenomenology which emanated from North America. His key criticism was that the 30 studies he reviewed were concerned with a third-person subjective description, or so called 'lived experience,' of the phenomenon being investigated, not a critical examination of the phenomenon itself (Barkway 2001). Crotty dubbed this lived experience research as 'new' phenomenology. Paley (1998) supported Crotty's assertions. Paley (1998) suggests that frequently social science researchers espousing a Heideggerian methodology concentrate on investigating the 'lived experience'; in doing so, the lived experience is frequently stripped of the world within which it takes place and is, as such, not consistent with Heideggerian philosophy but is in fact a betrayal of its key tenet, *dasein* (being-in-the-world). Paley argues that *dasein* is more complex than the lived experience- being-in-the-world encompasses more than one experience of it. In other words, the person's experience of the phenomenon is not *the* phenomenon. Despite the similarity in the line of argument Paley (1998) does not cite Crotty within his article nor acknowledge him as being a source of inspiration.

Both Crotty and Paley called for a more critical stance when accepting the participant's account of an experience of a phenomenon. Paley (1998, Page 821) suggested that nurse researchers adopting phenomenological approaches frequently assume the 'principle of incorrigibility'. This 'principle' is based on the premise that the person's experience is incontrovertibly theirs and that a participant's description is an accurate account of what their experience actually is like and is, as such, immune to censure. Crotty and Paley agree that this assumption does not fit with Heidegger's teachings. Darbyshire *et al.* (1999, Page 17) in response to Crotty's work, stated that 'unfortunately, he [Crotty] provided little or no textual evidence for the reader who wishes to understand the basis of his argument here'. Crotty (1996) argued that this uncritical

acceptance of subjective experience would not enlighten the phenomenon under investigation but could in fact emasculate nursing research. Whilst both Crotty and Paley both provide a critique of nurse researchers attempts at phenomenology, neither make any tangible suggestions as to how this research might be conducted.

Paley (2005) went on to highlight discrepancies between phenomenological rhetoric and phenomenological practice. Paley (2005) argues that phenomenologists typically value experiences, meaning, subjectivity and understanding rather than the concepts associated with science such as reality, objectivity and generalisability. Paley refers to several research studies to support his assertion that phenomenologists, albeit unwittingly, frequently translate subjective perceptions, meanings and accounts of understanding into claims about the objective world. Paley (2005, Page 107) accuses researchers of making 'claims about reality, aspire to a form of objectivity... and generalise widely from sample to population'. Considering the examples that Paley provides it is hard not to agree with him. Within the examples of research that Paley has selected there does appear to be an inconsistency in approach. A phenomenological researcher may espouse and promote individual, subjective perceptions at the outset of their research but by the conclusion find themselves overstating their results by generalising them to a wider population, making assumptions about causation, presenting participant's individual views as somehow authoritative. From personal experience I would suggest that these inconsistencies are not always a deliberate or even ignorant deviation from the underpinning philosophy but the author may be bowing to the expectations of Journal editors who frequently demand statements of the international significance of findings, clear and definite implications, and their significance to nursing. It is therefore perhaps understandable that in order to ensure publication in a high impact journal, authors are tempted to over egg the pudding.

Dowling (2007) points out that the arguments put forward by Crotty (1996) and Paley (1997; 1998) whilst controversial, have placed a spotlight on phenomenology which has helped expose its complexities. Indeed many scholars have responded to the criticisms of Crotty and Paley. Crotty's work in particular has evoked passionate responses that have been polarised in nature (Barkway 2001). Benner (1996), the eminent North American nurse researcher, describes the book as 'uncritical and unobjective', which, as Barkway (2001) highlights, is the same criticism that Crotty aims at North American nurse researchers. Darbyshire *et al.* (1999, Page 17) assert that Crotty's interpretation is a 'narrow, existentialist view of Heidegger's work', which is often 'misguided and poorly informed'. Darbyshire *et al.* (1999) provide detailed justifications of their arguments supported by direct quotations from Heidegger. In contrast Porter (1998, Page 18) supports Crotty and Paley and suggests researchers have 'done phenomenology without knowing phenomenology'.

Caeilli (2001) suggests that the critiques of Crotty and Paley demand greater rigour both in the interpretation of the methodology and in the selection of research methods. However, Caeilli (2001, Page 275) suggests that researchers are frequently placed in an 'extraordinary indeterminate position'. It would seem that whichever method researchers choose, they will never satisfy all critiques. An unfortunate consequence of such criticisms, Caeilli (2001) suggests, is that in attempting to be true to its philosophical beginnings phenomenological researchers have become too reticent about how the research may be implemented. This reticence has led to a paucity of directive literature that offers tangible advice for addressing the procedural aspects of conducting a phenomenological study.

As Cailli (2001) highlights, prior to committing to documenting the chosen methods, as a researcher, I have to face the following challenges that the above debate has raised:

1. I must accurately interpret Heidegger's often complex work- a task for which, as a novice researcher, I am comparatively ill prepared. It requires full comprehension of the intricacies of phenomenology prior to engaging with the process of phenomenology. I feel that I am obliged to *know* the experience before having the privilege of living it.
2. I must seek guidance and understanding from the plethora of Heideggerian phenomenological research reports, much of which has been discredited by the likes of Paley and Crotty.
3. I must reflect upon my own research question and my research intention and critically, assess whether the two are the same. What do I mean by 'What are the patients experiences of technology within ICU?' Am I interested in the phenomenon of technology in ICU or the patients lived experience of it? Or are the two so intricately intertwined that they are indistinct?
4. I must then choose my methods which must be defensible from the philosophical and epistemological positions that guide the study (Caeilli 2001). In other words, which methods should I employ to make sure that the lived experience is not stripped of the context within which the experience was lived? In addition, I need to consider, what is practically and ethically possible?
5. Regardless of the above requirements, all must be achieved with little substantive direction from the literature, as despite there being an abundance of literature regarding the methodology of phenomenology there is very little on the actual methods.

Barkway (2001) suggests that researchers must choose a method that suits the purpose for their question. Indeed Van Manen suggests that the phenomenological 'way' (methods) cannot be determined by 'fixed signposts but should be discovered or invented as a response to the question in hand' (Van Manen 1990, Page 29). It is therefore at this point that I return to my primary research question as the focus of my decision making- 'What are patient's experiences of technology in intensive care?' The following section describes the pragmatics of undertaking Heideggerian phenomenological research in light of the philosophical discussions. I aim to explicate how I have overcome the challenges highlighted previously providing justification for the decisions I have made with reference to the 'question in hand' and the associated Heideggerian tenets.

Data Generation: Interviews

Introduction

Being-in-the-world, is central to Heideggerian understanding and philosophy (Heidegger 1962). According to Heidegger it is through language that being-in-the world is both manifested and understood (Leonard 1994; Van der Zalm and Bergum 2000; Maggs-Rapport 2001). Fundamental to this understanding is that the manifestation of being-in-the-world through language is inherently subjective to the person using the language. However, as is evident with consideration of the debate instigated by Crotty (1996), it is not just the subjective description of being-in-the-world that phenomenologists are interested in. As Benner (1985, Page 5) asserts the goal of Heideggerian research is 'to find exemplars or paradigm cases that embody the meanings of every day practices...in such a way that they are not destroyed, distorted, decontextualized, trivialised or sentimentalised'. Assurance that language may encapsulate all that it is to 'be-in-the-world' may be gained from Heidegger's notion that individuals are self

interpreting of an *a priori* world. An *a priori* world assumes an indissoluble unity between the person and the world (Koch 1995). Heidegger claims that interpretations of being-in-the-world are not generated in individual consciousness as subjects related to objects but rather are given in our linguistic and cultural, historical and social traditions and make sense only against a background of significance (Leonard 1994, Page 57). Therefore culture, history, and psychosocial context are intertwined with the language used to articulate our interpretations of being-in-the-world.

Freeman (2007) contends that expression through language is a meaning-making event that exhibits the particular conditions of the individual: characteristics, and the cultural, historical and ideological horizons that support or constrain the individual in their understanding. With reference to investigating being-in-the-world, Leonard (1994, Page 58) suggests that 'human behaviour becomes a text analogue that is studied and interpreted in order to discover the hidden or obscured meaning'. Therefore it follows that it is through language that being-in-the-world in its entirety can be articulated and shared. Because our everyday lived experience is so taken for granted as to go unnoticed, articulation through language may achieve flashes of insight into being-in-the-world, however, it is important to note that the taken-for-granted, everyday lived world can never be made completely explicit (Leonard 1994, Page 59).

Heideggerian research therefore adopts the underlying premise that people articulate their understanding of the world through language. Data may come from interviews, participant observations, diaries and samples of human behaviour (Benner 1994). Traditionally, insights into people's experiences are gained by encouraging articulation of experience and understanding of the experience within an interview. Price (2002) asserts that interviews often appeal to nurse

researchers as the process of interviewing is familiar from clinical work and offer the potential to enter the world of patients and their health or illness experiences. Johnson (2000) suggests that eliciting stories and narratives of experience by interview preserves the cultural and historical context of the phenomenon and enables the significance and meaning of the experience to be revealed.

Interviews are often considered the most appropriate method of data collection in Heideggerian phenomenological research. Adopting an interview approach however, presents its own challenges. Gordon (1998) suggests that, to many, an interview is merely a conversation with a purpose with their conduct a relatively straightforward affair; however interviews, particularly phenomenological interviews are more complex than this. The characteristics of interview for the different naturalistic methodologies which themselves have blurred boundaries, are not completely distinct (Sorrell and Redmond 1998). Frequently, the pragmatics of the interview process are often indistinguishable however the underpinning purpose or intention may differ.

Phenomenological interviews are particularly complex as there is little detailed guidance, from literature on how to tailor the interview to fit the specific research methodology. In particular within the literature frequently authors do not stipulate the exact methods which they are adopting or if they do they do not give explicit details of the distinguishing features of the interview process. Often the interview methods described are the same regardless of the chosen methodology. Starks *et al.* (2007) go as far as to suggest that there is little difference in interview technique between phenomenology (although they do not stipulate what type of phenomenology) and grounded theory (again without stating which branch of grounded theory). They also draw parallels between phenomenology and discourse analysis interview

techniques. However, many of Starks *et al.* (2007) assertions are unsubstantiated by any literature or philosophical teachings. Since it was never Heidegger's intention to develop a research method there is little pragmatic guidance regarding interview technique from him either.

It is therefore necessary to clarify what distinguishes a phenomenological interview from any other naturalistic interview. The phenomenological interview should have congruence between the Heideggerian philosophical tradition and the interview method. At the same time, attention must be paid to the interview technique as the way in which an interview is approached and conducted has a bearing on the overall nature and quality of data generated and subsequent analysis (Hallet 1995; Lowse and Prowse 2001). A balance between conducting a quality interview which generates quality data that is specific to the research question and adhering to the minutia of the research methodology must be sought (Lowse and Prowse 2001).

Purpose of Phenomenological Interviews

The purpose of phenomenological interviews is to make explicit the meanings embedded in the participants language used to articulate and describe a phenomenon within its context. Heidegger suggests that meanings are embedded and often concealed in cultures which incorporate shared languages and practices (Sorrell and Redmond 1998). The goal of a phenomenological interview is to construct a text that is both strong and insightful a representation that brings to mind the phenomenon described (Kleiman 2004). Therefore the purpose is not to explain, predict or generate theory but to gain insight into and understand shared meanings (Koch 1999). The key phrase is 'shared meaning'. Shared meaning is a term that is often used in research literature but is seldom clearly defined. It is not clear whether

'meaning' is shared between the participant and researcher or between multiple participants. Frequently the phrase is used to imply both. Primarily I will discuss this phrase in terms of shared meaning between researcher and the participant- the latter will be discussed later in terms of data analysis.

Being-in-the-world and the assumed indissoluble unity between a person and the world will apply to the researcher as much as it does to the researched. The researcher as a person, being-in-the-world infers that the researcher's pre-understandings, cultural, historical and psychosocial context will be as present within the interview as it will be for the participant. Therefore the phenomenological interview will incorporate the researcher's pre-understandings cultural, historical and psychosocial context in the generation of data. Lowse and Prowse (2001) suggest that this is a legitimate part of the research process and should not be left out. The products of a phenomenological interview are therefore in essence co-created by the researcher and the participant in as much that within any interaction each one will have an influence over the response of the other. The resulting dialogue will therefore represent both the researcher's and the participant's and by inference a 'shared' understandings of the phenomenon in question. This is often referred to as co-construction.

During the co-construction of 'shared meaning', the researcher is obliged to acknowledge that the past is reconstructed in the light of the participant's present awareness (Flood 2010). As the researcher attempts to co-construct understanding, interpretations of the participant's original dialogue are made and in effect, the story is re-told. In the re-telling of the story certain features are related to others in new ways with the researcher's contribution helping the participant to create a new narrative which is jointly authored or co-constructed (Debesay *et al.* 2008).

Therefore, participants may reconstruct the telling of their experiences to convey a specific perspective of an event. As such it is meanings and not necessarily a singular truth that is conveyed.

The purpose therefore is not to gain an objective decontextualised truth but gain insight into the participant's own experience (Bailey and Tilley 2002). From this perspective research does not provide a mirror image of social world, it may provide access to the meanings that people attribute to their experiences of the social world (Gordon 1998). They represent personal understandings of experiences which are vital for the understanding of and provision of care.

The purpose of the interview is to facilitate the co-construction of meaning. The Heideggerian interview is therefore a dynamic interpersonal encounter in which the participant is not portrayed as a repository of knowledge to be excavated or explored, but rather as an active co-creator of meaning (Koch 1999). Several authors have distinguished the Heideggerian interview as a process of data generation rather than the more passive notion of data collection (Gordon 1998; Lowse and Prowse 2001).

Style of Phenomenological Interviews

An engaging conversation

Heideggerian interviews are frequently referred to as conversations rather than interviews to reflect the mutuality of the process (Van Manen 1990; Draucker 1999). Gadamer argues that you cannot conduct an interview anymore than you can conduct a conversation suggesting that 'the more fundamental a conversation is the less its conduct lies within the will of either partner' (Gadamer 1982 p345). Gadamer (1982) suggests that we fall in to conversation, the

direction and outcome of which cannot be predicted. The conversation has a spirit of its own and the language used in it bears its own truth. Finch (2004) suggests that understanding a patient's situation or a lived experience evolves from a health care professional's sincere communication with the patient.

Kvale (1996) argued that by regarding a phenomenological interview as an engaging conversation between participant and researcher allows participants to give authentic accounts of their experiences and give a deep insight into the phenomena. Bailey and Tilley (2002) suggest that both researcher and participant may experience a catharsis from mutual conversation as they are empowered through awareness of new meanings in lived experiences. Each conversation or interview therefore has a uniqueness which should be valued and nurtured. Smythe, *et al.* (2008) suggest that to go into an interview with a mind set of conducting it is to freeze the phenomenological spirit. Therefore an interview must not be structured in that a pre-organised plan is followed nor unstructured where there is no clear sense of why you are there.

It is clear from many authors' assertions that in order to gain insight into the participants being-in-the-world, Heideggerian phenomenological researchers must aspire to engage in fundamental or engaging conversations (Gadamer 1982; Kvale 1996; Koch 1999; Bailey and Tilley 2002; Smythe *et al.* 2008) or as Finch (2004, Page 253) describes it 'sincere communications' rather than conduct an interview. Authors discussing interview methods or reporting on research clearly have an idea of what a phenomenological interview *should* look like, however, none disclose how this may be achieved. Equally as nebulous are the exact constituents of a fundamental, engaging conversation or sincere communication.

The following section represents a suggestion of measures that might be taken to ensure an engaging conversational style. It is important to note that these pragmatic suggestions are based on my personal interpretation of the philosophical requirements of conducting a Heideggerian phenomenological interview. Measures include management of power, interpersonal skills, and an emic position.

Management of power

The researcher has the responsibility of allowing freedom of conversation to engage the phenomenological spirit whilst leading the direction of the interview to achieve research objectives. This has implications for the management of power between the researcher and the participant. Co-construction of meaning and the supposed mutuality of the interview process might lead one to assume that there is a non-hierarchical relationship between interviewer and interviewee. In other words researcher and participant would have mutual engagement with the conversation such that it flowed freely and in any direction. However, the researcher who has certain research objectives may naturally albeit unwittingly lead the participant's dialogue in a certain direction. Conversely participants, who may feel flattered to have been asked to share their experiences frequently seek to please the researcher with answers that are believed to be what the study requires (Price 2002). Both interviewer and participant may hold back part of what is in their power to disclose (Cohen *et al.* 2003). Arguably the very nature of a researcher collecting data about a participant, from the participant assumes a hierarchical relationship (Melia 2000). It is therefore reasonable to assume that there could be an unequal relationship between interviewer and the interviewee. The key issue for the researcher is therefore to seek a balance between the desires of the researcher and the participant when establishing the direction of the dialogue and ultimately the research.

Measures to ensure a free flowing mutual conversation included the following. Rather than using a pre-determined list of questions, an interview topic guide was used. This outlined broad topic areas that reflected the research aims. There was no set or pre-determined order of discussion of topics. Topics from the interview topic guide were introduced with consideration of the participant's responses and at convenient and relevant points during the dialogue. I did not utilise fixed vocabulary but spoke *ad libitum* according to participants' responses. Equally participants were given the opportunity to speak with minimal interruption and direction from the interviewer. When the participant strayed from the topic area, at a convenient juncture, such as a natural pause during the participants account, I prompted the participant to consider their experiences in relation to the research aims, therefore not discounting their account but simply re-focussing it.

Interpersonal skills

The manner in which interviewers evoke participants recall, information, expression and feelings have a direct impact on the quality of the data obtained (Sorrell and Redmond 1998). Every interview response is influenced by or reflects the speaker's interpretation of the preceding response which means that both the researchers' and participants' experiences are reflected in the data (Lowe and Prowse 2001). The researcher therefore needs to be mindful of the potential impact that their own verbal and non-verbal communication may have on both the responses the participant may give and ultimately the quality of the data generated.

It may be necessary to build up a rapport with the participant before natural and fundamental narrative flows. Langridge (2007) suggest that the interview should be a relaxed affair, allowing the participant time to chat and wander off the subject as a steely grip on the interview may

lead to tension. Working at the participants pace, slowing down and speeding up when necessary will also allow the participant to feel at ease when delivering their account (Finlay 2006).

The interviewer needs to evoke responses that are natural to the participant rather than them fitting their responses to preconceived categories or interpretations. Some participants (who are perhaps naturally more reflective) may try to fit their responses into perceived known criteria anyway (Bailey and Tilley 2002). For example, some patients who have been a patient on ICU may access information, internet sources, support groups who may discuss coping with critical illness, post-traumatic stress, the stress response or adjustment to disability. The participants may then subsequently fit their responses to match or reflect the information that they have accessed.

The researcher therefore needs to be constantly reflective of the participants and their own contributions to the conversation. In addition the co-construction of meaning relies on the blend of listening and the participants' accounts. Sorrell and Redmond (1998) recommend that the interviewer must adopt an active approach to listening as this shapes the researchers interpretation of what is happening during the interview. Active listening is frequently cited with regards to research interview technique, however, is seldom defined. I therefore sought clarification of this term by looking in the more generic, clinical literature. Much of the guidelines and definitions relate specifically to patient consultations or counselling. Although the goals of a patient consultation and a research interview are fundamentally different both aim to gain insight and understanding of a patient's experiences. Therefore some of the guidelines and recommendations may be relevant and transferable to the research interview.

Robertson (2005) describes active listening as a specific communication skill which involves giving free and undivided attention to the speaker. This infers placing all of one's own personal concerns, distractions to one side and giving all of your awareness and attention to the speaker. This is a difficult discipline as several authors acknowledge (Robertson 2005; Shattell and Hogan 2005; Bryant 2009). Active listening requires intense concentration and incorporates both verbal and nonverbal communication.

Bryant (2009) states that the listener will demonstrate that they are listening by the way they stand or sit, focusing on the person talking and having eye contact. Bryant recommends sitting slightly forward in the chair with hands still. Giving eye contact enough so that the person thinks you are listening but not so much that you are threatening. Making notes or referring to the interview topic guide may be important during the interview. However, this needs to be done at a convenient time- in other words give participants your full attention for an amount of time, then make note, check information before giving them eye contact again to reassure them of your interest.

Some communication styles can inhibit understanding. Shattell and Hogan (2005) suggest that questions beginning with the word 'Why?' are not as helpful as those that begin with phrases like 'Tell me more about...' or 'What was that like?'. They suggest that 'Why' questions take people out of their descriptions of their current experiences or feelings and channel them into either an intellectual or defensive response. Comments conveying complete understanding such as, 'I totally understand' also may inhibit understanding as it sends a message to the participant that no more needs to be said when actually they may well have had more to add.

Sorrell and Redmond (1998) suggest providing non-verbal nods and maintaining eye contact as a means of maintain the participants flow. Such strategies are necessary to communicate interest in the participant's dialogue (Sorrell and Redmond 1998). However, Langridge (2007) and Van Manen (1990) emphasise the importance of silences. Van Manen (1990, p112) suggests that out of silence a more reflective response may ensue.

As well as actively listening to the participant's account, utilising strategies to maintain participant flow, the researcher needs to simultaneously reflect and interpret it in terms of their own presuppositions. The results of this reflection must then be shared with the participant who may reflect on the understanding further as a means of obtaining shared or co-constructed understanding. Listening, reflecting and interpreting simultaneously may offer somewhat of a challenge to the researcher. The level of concentration required to do this effectively is high and sustained. This has implications for the length of the interview and the number of interviews carried out with each participant. In light of not only the researcher's concentration levels and the potential vulnerability of the participants, the interviews lasted between 60-90 minutes. In addition, I only conducted one or two participant interviews in one day.

An emic position

In order for co-construction to occur the phenomenological researcher must take an emic position. An emic position is a term first utilised in anthropological studies that describes an account from within a culture as opposed to an account from an objective observer or etic position (Harris 1976). In research terms this means that the researcher is entrenched within the research and the researched. The researcher therefore acknowledges and embraces their own culture, historical and social experiences that may influence the research method. Van Manen

(1990) noted that the emic position is a defining characteristic of phenomenology. It is therefore impossible to not let the researcher's enthusiasm and interest in the phenomenon influence the collection and findings and interpretations. Researchers presuppositions are likely to influence how researchers select and conceptualise problems and how they interpret their findings (Lowse and Prowse 2001).

Exploration and elucidation of the researcher's personal, emotional, historical and social interests and investment into the study adds to the significance of the study for the researcher on an individual level but also within the wider context of society (Lowse and Prowse 2001). The researcher's background, prior knowledge and preconceptions of the study phenomena are therefore entwined with the research, influencing their responses to participant's data generation and analysis (Lowse and Prowse 2001). Wimpenny and Gass (2000) suggests that the relationship between the researcher and the researched is distinctive to the phenomenological interview as it acknowledges that the researcher is an important component in the research process.

An emic position may ensure an engaging conversation as acknowledging that the researcher has as much to add to the understanding of the phenomenon as the participant means both researcher and participant are contributing to the conversation and may ensure full engagement with the process. Submersion of the researcher into the phenomenon and understanding of the phenomenon may lead to an enthusiasm that will influence the dialogue between themselves and the participant encouraging a free flowing conversation rather than a question and answer style of interview.

Structure of phenomenological interviews

Number of interviews

Arguably the requisite level of rapport necessary to share personal meanings, especially in relation to sensitive topics is difficult if not impossible to achieve in a one off interview. Gordon (1998) suggests a one off interview does not sufficiently acknowledge the social and cultural context in which the data was produced and may lead to context stripping of the data. Wimpenny and Gas (2000) recommends a three stage interview process which begins by establishing context of the interviewees' experience, through to construction of the experience and finally a reflection on the meanings it holds. Walters (1995a) also suggest that multiple interviews allow the Heideggerian researcher to continually reflect on the development of understanding and refine this understanding as new insights emerge. Development and refinement occurs as the researchers' exposure to the phenomenon increases (Wimpenny and Gass 2000). However, with multiple interviews there is a danger that the interview is driven by emerging theory rather than the individual account. Conversely the involvement of the researcher in the construction of data is essential therefore it maybe considered of no consequence if the researchers involvements incorporates experiences and understanding from previous interviews.

It would appear that many authors espousing to Heideggerian phenomenology purport that multiple interviews with each participant maximises the development of researcher participant rapport hopefully leading to a more authentic account, prevents context stripping and facilitates co-construction of understanding (Lowse and Prowse ; Wimpenny and Gas 2000; Walters 1995; Gordon 1998). Interestingly, many published reports of studies utilising Heideggerian phenomenological only report carrying out a single interview with participants. Therefore, whilst

there are perceived theoretical advantages to carrying out multiple interviews, clearly many researchers choose only to do one. The reasons for this are not made clear in the research reports.

It might be suggested that a one off interview may be more pragmatic for researchers with finite time and resources. In addition the researcher would need to consider the ethics of making high demands on the participant's time, particularly given the vulnerability of the potential participants. In addition, discussing issues with somebody unrelated to their experience, knowing that they will never see them again may actually facilitate free and honest dialogue between the participant and the researcher. On balance of the above discussions and with consideration of the pragmatics of the particular research site, access to the participants and their vulnerability, this study interviewed each participant once.

Unstructured versus Semi-structure

Unstructured conversations that encourage participants to share their stories and to uncover common meanings in their experiences offer the most authentic insight into understanding of the phenomenon in question (Finch 2004). Annells (2006) argued that in order to comply with the Heideggerian philosophy, only one initial question is required (What is your lived experience of...?), based on the premise that the process will generate enough data without further guidance to the participant. The traditional guidance to researchers conducting interviews is that the researcher should say as little as possible and encourage the participants to talk in an untrammelled way about the issues under discussion (Melia 2000).

An unstructured interview format, whilst philosophically sound is near impossible to carry out and not always appropriate. An unstructured or open interview may complement the ethos of phenomenology, however, Van Manen warns that 'one needs to guard against the temptation to let method rule the question, rather than the research question determining what kind of method is most appropriate for its immanent direction' (1990, Page 66). Britten (1997) also asserted that interviews need a degree of structure to ensure that the data generated is relevant to the research question. As Van Manen suggests, 'It is important to realize that the interview process needs to be disciplined by the fundamental question that prompted the need for the interview in the first place' (Van Manen 1990, Page 66). The interview therefore must identify the appropriate balance of structure and flexibility (Sorrell and Redmond 1998). This was achieved in this study by the use of an interview topic prompt list. The use of the prompt list permitted the participant to voice their genuine views, feelings and opinions without constraint whilst focussing on the phenomena in question (Hallet 1995). In addition, participants welcomed some guidance on what to talk about. The prompt list also helped to generate data that addressed the research questions.

Questioning

Most interviews commence with an open-ended question and eventually narrow the focus as clarifying questions are asked and themes emerge. The researcher may respond to important content response and general non-verbal cues (Sorrell and Redmond 1998). Price (2002) described a process of laddered questioning which attempts to address the practical, methodological and ethical issues associated with interviews. Laddered questioning operates on three levels- questions about actions, questions about knowledge and questions about philosophy. Price (2002) recommends starting with action questions which are considered to be

least invasive. Action questions involve descriptions of actions or events. Knowledge questions are employed later in the interview only when the participant shows signs of relaxing and are starting to engage with the developing narrative. Knowledge questions ask 'what do you think...?', 'how did you react...?', 'What do you know...?' (Price 2002). The most invasive questions are questions about philosophy which concerns beliefs, values and deep-seated feelings. Questions about the participant's beliefs and feelings may give the most insight into the phenomenon.

Whilst there is a certain attraction to Price's (2002) ladder approach to questioning, the systematic style arguably may fetter the phenomenological spirit- questions need to follow the flow of the conversation rather than occurring in a pre-ordained sequence. This approach may also deny the researcher the opportunity to reflect on the conversation and make their own contributions. The exact nature of the questions used within the interview were not pre-ordained, however, the interview topic guideline was used to offer a broad framework.

Probes

The aim of a Heideggerian phenomenological interview would be for the participant to become engrossed in the unfolding narrative as the vividness of the original experience returns (Price 2002). However, verbal or non-verbal probes may be required to enhance the description of the lived experience. Clarification of ambiguous words or phrases may also be achieved by probing (Clayton and Thorne 2000). Probing during the phenomenological interview may assist the participant in recalling and reflecting on experiences and bring forth contextual details important to the meanings embedded in the narrative (Debesay *et al.* 2008). Lowse and Prowse (2001) suggest that probes help to elicit truthful and authentic co-constructions of meaning.

Open questions with probing also maximises interactive opportunities between interviewer and participant allowing for a close and engaging relationship to develop, which ultimately reduces the likelihood of socially desirable answers (de Witt and Ploeg 2006).

The benefits of probing are clear however, there are some potential disadvantages to probing which must be considered. Price (2002) suggests that if excessively probed, participants may become anxious that what they are saying is not relevant or is unclear. In addition a researcher may have difficulty in sustaining their concentration for the entirety of the interview and may have difficulties in thinking on their feet, gathering information and deciding where and how to probe for further information (Russell-Bernard 2000). Researchers therefore needs to identify when and how to probe (Price 2002).

Russell-Bernard (2000) described seven types of probes that may be utilised:

- Silent Probe- akin to an 'Epistemological silence' (Van Manen 1990)
- Echo Probe- repeating last point
- Uh-huh Probe- positive encouragement
- Tell me more- invite participant to tell you more about a particular issue raised
- Long Question- asking for a full answer
- Probing by leading- asking a provocative question
- Baiting- implying that you already know something in order to prompt the participant to reveal more

Some of the suggested probes above are more useful than others. The researcher must probe in an ethical manner, without compromising the power relationship and without interrogating the

participant. Probing by baiting and by leading are arguably controversial interviewing techniques and inconsistent with an ethical approach. I therefore elected to not use these approaches, not least because the chosen methodology requires an honest and trusting relationship between researcher and participant. Baiting and leading the participant does not facilitate an equitable relationship between researcher and the researched or ensure the co-construction of understanding but rather assumes the researcher to be in a position of power and influence over the participant. I therefore predominantly utilised the positive encouragement probes such the echo, uh-huh and tell me more probes. I adopted a discretionary approach to the silent probe as for some in certain situations silence may be uncomfortable for both the participant and the researcher.

Pilot Interviews

Pilot interviews offers the researcher the opportunity to try out a variety of openings and probes before undertaking actual interview and help avoid situations where participants respond with long silences confusion or irrelevant chatter (Sorrell and Redmond 1998). A pilot interview was therefore used to test the adequacy and further define topics on the interview prompt list. The pilot interview method is in line with the emergent nature of phenomenological research with themes developing as the study progresses (Denscombe 2002). As a relatively novice researcher, the pilot interview also offered an opportunity to gain valuable experience in conducting phenomenological interviews.

Access and Sampling

The research took place within the adult intensive care unit at a teaching hospital in the South of England. Permission was gained from the modern matron, and clinical director of intensive care.

Approval was gained from the Hospital Trust Research and Development Department and the NHS Research Ethics Committee.

I sampled patients from the population of all patients admitted to ICU who met the inclusion criteria. I aimed to recruit 30-35 participants, however, I stopped recruiting at 19 participants as data saturation was achieved at this point.

Inclusion Criteria

- Participants will have been an in-patient within ICU for four or more days
- Participants will have been discharged from ICU
- Participants will be able to communicate independently utilising aids and adjuncts as necessary (E.g. phonate valve, paper and pencil)
- Participants will be capable of giving informed consent
- Participants will feel well enough to participate
- Participants will be able to speak English

Exclusion criteria

- Participants who were in ICU less than four days
- Participants who are unable to communicate independently
- Participants who do not feel well enough to participate
- Participants who remain in critical care

Recruitment

At 3 months after discharge from ICU, all patients are invited by letter to attend an ICU follow-up clinic. Approximately three weeks later, about a week prior to the allocated follow-up clinic appointment the administrator in ICU telephones the patient to confirm attendance. Patients then attend clinic at an allotted time and day. In order to minimise the inconvenience to both the potential participants and the ICU staff, I utilised this already existing system to recruit a convenience sample of participants.

All patients eligible to attend the follow up clinic, who meet the inclusion criteria, were invited to participate in the research by letter. The ICU administrator placed the pre-prepared research invitation letter in with the invitation to attend follow up clinic. A participant information sheet was included within the research invitation letter. Within the research invitation letter and participant information sheet my contact details were given. Participants interested in hearing more about the study were given the option of contacting me directly by telephone, email or postal address. Alternatively, at the same time that the ICU administrator telephoned the patient to confirm attendance at the follow-up clinic (approximately three weeks after receipt of invitation and patient information sheet), the administrator asked the patient if they would like me, the researcher, to telephone them about the study. If they said yes the administrator, with the patients consent, advised me of the patients name and time and date of their follow-up clinic appointment and their home telephone number. I then telephoned the potential participant and answered any questions that they had and clarified the information sheet if necessary. If the potential participant consented to take part I arranged a time convenient to them to meet them either before or after their follow up appointment. Written informed consent was then gained immediately prior to the interview.

Data Analysis

The results of an interpretive phenomenological inquiry are a text or story that gives insights into the phenomenon under study and the meanings associated with it. The challenge of the phenomenological researcher is to foster analyses that are faithful to the data (Halling and Leifer 1991). Halling and Leifer (1991) suggest that being faithful to the data, to experience as lived, is a challenge requiring more than organising the participant accounts of their lived experiences into themes. The crux of Heideggerian phenomenology is that the researcher is as much 'being-in-the-world' as the participant. As with all other aspects of Heideggerian phenomenology, the nature of data analysis is at the heart of much controversy and debate (Whitehead 2004). The debate relates to the extent to which the researcher's forestructures are made explicit during the research process. It is generally accepted that the researcher's forestructures are integral to the process but the literature does not clearly explain to what extent they should be explained or revealed. Neither does the literature clarify if it is enough to accept that forestructures formulate the interpretation without necessarily knowing what those forestructures are. Arguably, people may neither have enough of a degree of self awareness and reflexivity to even be able to explicitly identify those forestructures, nor explain how they may influence their own understanding. Measures to ensure openness of my forestructures and how they influenced the data analysis are discussed in the subsequent section.

Within the literature there appears to be a pressure on the researcher to adopt a systematic approach with defined steps and tasks which provides a clear audit trail of how understanding and interpretation of the phenomenon was achieved. However, arguably the phenomenological spirit is not that mechanical or linear. Notwithstanding the above debate Van Manen (1990)

described a framework of data analysis that may inform Heideggerian phenomenological approaches. The steps are outlined below:

- The interview transcripts will be carefully read and re-read
- Preliminary comments may be added to the interview transcripts which may include summaries, associations or interpretations
- Significant statements or phrases that are particularly pertinent to the patients' experience of technology in ICU will then be highlighted
- Essential themes and statements that reflect the overall context of the data will be identified
- Essential themes common to all the participant's interview transcripts will be identified. Differences will be highlighted
- Common links between themes will be identified. Some themes may cluster together, while others may be broken up further
- Themes may be re-ordered and structured
- Themes will be checked by continually returning to the original interview transcript
- Participant quotations that exemplify the essential themes are selected

I utilised the above guidelines somewhat mechanically at first. As my engagement with the phenomenon increased I was able to adopt a more fluid approach to these stages. As my experience and expertise developed, a more intuitive and heuristic approach to data analysis and interpretation was adopted. This approach complements the emergent nature of Heideggerian phenomenology.

Research Quality and Rigour

The quality of qualitative research has been the subject of much debate and controversy. Rolfe (2006, Page 304) refers to this debate as the 'quality muddle' which seems a reasonable description of the polemic debates, conflicting paradigmatic and philosophical discussions which exist within the social science and nursing literature. Meyrick (2006) suggests that the debate is not a fruitful one and actually eclipses the needs of health care researchers to apply the findings of their research. Despite the prolific discussion of the nature of quality and rigour in qualitative research there remain many unanswered questions and challenges. Rolfe (2006, Page 203) suggests that the continued failure to agree on universal criteria for judging quality in qualitative research is symptomatic of an inability to identify a single coherent qualitative paradigm. In other words a one size fits all approach to assessing rigour is impossible for the broad scope of naturalistic methodologies.

Given the nature of Heideggerian phenomenology as a philosophy rather than a specific research methodology, researchers are further challenged to decide how the notions of quality and rigour may be applied to research informed by Heideggerian thought. The following section aims to outline the key discussions regarding assessing quality and rigour of qualitative approaches, specifically Heideggerian phenomenology. I will then go onto outline and discuss some of the key criteria that may be applicable to this study.

Defining rigour

There are no clear definitions of what constitutes quality and rigour in qualitative research. Davies and Dodd (2002, Page 280) state that 'rigour is the authoritative evaluation of good research and the unspoken standard by which all research is measured'. The key words in this

phrase are 'unspoken standard' as within the literature there is indeed an inferred expectation that qualitative researchers should clearly explicate a defined set of criteria with which to judge the 'quality' of the research, however, there is no agreement of what these criteria should be. Many authors suggest that the criteria used to ensure quality should be consistent with the philosophical and methodological assumptions on which the research is based (Lincoln and Guba 2000; Koch 2006; Rolfe 2006; Ajjawi and Higgs 2007). Criteria such as credibility, transferability, trustworthiness, auditability, resonance among others have been suggested and indeed adopted as a means of evaluating qualitative research rigour. These criteria are predominantly based on the works of Lincoln and Guba (1989; 2000). These criteria often reflect similar criteria that are applied to quantitative research- credibility has been likened to validity, trustworthiness to reliability, transferability to replication and so forth. The concept of rigour appears therefore to have a quantitative reference.

The use of criteria in itself has evoked much debate. Hammersley (2008) and de Witt and Ploeg (2006) highlight that a defined set of universal criteria are inappropriate for qualitative methodologies and may impede the full expression of rigour within specific methodologies. Both authors go onto suggest a more fluid set of guiding principles and relevant considerations that may be reflected upon. A reflective approach to rigour is certainly more consistent with Heideggerian phenomenology.

De Witt and Ploeg (2006) utilised an evidence based approach to deriving a framework for appraising rigour specifically of interpretive phenomenological nursing research. The authors conducted a systematic critical review of interpretative phenomenological nursing literature published during 1994-2004. The framework derived from the literature was then further

informed by van Manen's (1990) work and Madison's (1988) criteria of rigour. De Witt and Ploeg (2006) describe the final framework as including expressions of rigour rather than fixed criteria thus inferring a more flexible and reflective approach to evaluating rigour. The expressions of rigour were described as balanced integration, openness, concreteness, resonance and actualisation.

Given that this study is informed by Heideggerian phenomenology I believe that the expressions of rigour are more amenable to the chosen research approach. The following section describes the expressions of rigour suggested by de Witt and Ploeg. I also intend to justify my choice of this framework by relating to other literature as well as the Heideggerian philosophical tenets.

Balanced Integration

De Witt and Ploeg described balanced integration as having three characteristics:

1. Clear explication of the philosophical approach adopted
2. Assimilation of the research philosophy with the research methods and findings
3. Balance between the voice of the study participant and the philosophical explanation

These characteristics have been highlighted by many other authors as being essential quality indicators (Guba and Lincoln 1989; Paley 1998; Koch 2006; Meyrick 2006; Rolfe 2006; Hagens *et al.* 2009). The difficulties in cohesively realising Heideggerian philosophy into definitive research methods have been discussed extensively in the above section. It is hoped therefore that the influence of Heidegger on the chosen methods has been made explicit. Where decisions have been made that do not sit comfortably with Heideggerian thought, I have aimed to give

adequate practical justification. Given the attempts to clarify the practical execution of a phenomenological interview it is hoped that there is an adequate balance of the study participants and the philosophical explanation.

Openness

De Witt and Ploeg (2006) argue that the notion of openness encourages opening up the research process to scrutiny. Openness may be achieved by reflexivity by the researcher of the process and detailing a clear audit trail. Lowse and Prowse (2001) suggest that the quality of the reported findings rests not only on the procedures used to generate and analyse findings but on the self-awareness of the researcher throughout the research process. Koch (2006) agrees and highlights that self-awareness of the researcher is essential to the research process.

Reflexivity is described by Rice and Ezzy (1999, p158) as 'An acknowledgement of the role and influence of the researcher on the research project. The role of the researcher is subject to the same critical analysis and scrutiny as the research itself' (Draucker 1999). The notion of *dasein* or being-in-the-world reminds the researcher of their inimitable relationship with the phenomenon and the context within which that phenomenon occurs. As such the researcher has potential influence on both the interview process and the interpretation of the participant's responses (Lowse and Prowse 2001). Chesney (2000) suggests that the researchers beliefs and background form the basis on which the choice of methods are based. Geanellos (1998) suggests that reflexivity is integral to Heideggerian phenomenology as it is essential in helping to reveal pre-understandings or fore-structures of a phenomenon. Careful reflection of the researchers pre-understandings helps to distinguish the researchers own understanding, assumptions and beliefs from the phenomenon under investigation (Geanellos 1998). Once

explicated the researcher must reflect on the forestructures and take into account their influence on the researcher and the research (Geanellos 1998; Koch and Harrington 1998).

It is therefore important throughout the research process to reflect on the impact of the researcher on the research in a reflexive journal (Koch and Harrington 1998; Koch 2006). Explicating the reflexive process as a means of understanding the impact of the researchers' views and values is a means of adding credibility to the research (Corben 1999). The account of the researcher's reflexivity is integral to the co-construction of data with the participant and also the subsequent interpretation and analysis.

De Witt and Ploeg (2006) emphasize that openness should be attended to throughout the research process rather than just a *post hoc* reflection therefore a reflexive journal should be used as an integral part of the research process. The use of transcript, personal and analytical files may also assist in achieving transparency of the research process (Ajjawi and Higgs 2007). A reflexive diary is often referred to as ensuring auditability or providing an audit trail (Draucker 1999; de Witt and Ploeg 2006; Ajjawi and Higgs 2007). A reflexive diary must therefore include clear explication of the theoretical, methodological and analytical decisions made throughout the research study (Horsburgh 2003; Koch 2006). Lincoln and Guba's (1985) seminal work first outlined the notion of auditability which they described as the extent to which the researcher makes actions clear to the reader. Lincoln and Guba (1985) regard audit trails as one of the principal techniques for establishing the conformability of qualitative findings. Some authors suggest that the credibility of the research may be enhanced by the construction of an audit trail (Sandelowski 1988; Koch 1995; Rolfe 2006).

Whilst many authors cite an audit trail as being a marker of rigour, few fully explain to which standards the work is audited. Some commonly cited standards: are extent and nature of researcher influence on the researcher (Annells 1999; Cutcliffe and McKenna 1999; Draucker 1999; Chesney 2000; Maggs-Rapport 2001; de Witt and Ploeg 2006), clear decision trail with justification of decisions made (Cutcliffe and McKenna 2004; Whitehead 2004; Koch 2006; Rolfe 2006; McNair *et al.* 2008), transparent progression of the development of themes (Van Manen 1990; Maggs-Rapport 2001; Cutcliffe and McKenna 2004; Whitehead 2004). However, arguably the auditable measures described above are contradictory to the phenomenological philosophy. According to Heideggerian thought, being-in-the-world is so fundamental that people aren't capable of explicating their relationship with the phenomenon in a way that is auditable. Can therefore we ever know or measure the influence the researcher has on the research given that the relationship between the researcher and the research is so inimitable? In addition reflexivity is rarely a linear process. As such decisions regarding the research approach and methods made may not necessarily follow an easily traceable trail.

In order to maintain openness I adopted a reflexive approach to the whole research process. Primarily I feel that reflexion is essential to the Heideggerian phenomenological process. A reflexive diary was kept into which general reflexions and accounts of decisions were logged. Prior to conducting any interviews I reflected on what it might be like to be a patient in ICU. In particular I examined my own preconceptions relating to technology and documented them as a means of enhancing the exposition of the phenomenon under investigation. Immediately after each interview I jotted down my initial impressions and interpretations of the patients narrative. After I had transcribed each interview I documented my further reflections on the data in the reflexive diary. As well as reflections on the data generated I also documented reflections on the

interview process highlighting strengths and weaknesses of my interview technique which could then inform subsequent interviews. During data analysis process I was then able to use the reflexive diary to examine my preconceptions, initial interpretations and deeper reflections on the data which contributed to the development of the themes. Although I have argued that provision of an audit trail *per se* neither sits comfortably with Heideggerian phenomenology nor necessarily is a marker of rigour, in maintaining a reflexive diary and field notes my decision making process are transparent throughout the research process. An extract from my reflexive diary together with a commentary as to how the reflexions informed the development of themes is provided in Appendix 7.

The cited requirement for the transparent progression of theme development poses an obstacle for the Heideggerian researcher. The inference is that by being transparent the independent auditor can then validate the process under which the interpretations were made and by default validate the interpretations. Indeed, Burnard (1991) maintains that the credibility of themes generated may be enhanced by gaining an independent validation. However, the phenomenological data generation and analysis process is underpinned by the co-construction of meaning between researcher and participant. Therefore only those involved in this co-construction process will be able to corroborate and validate themes generated. Another problem with independent validation is that if more than one person agrees with theme categorisation then it is viewed as more accurate than one person's interpretation. If this argument is expanded then it begins to support a positivist assumption that there is only one accurate reality. Conversely, it may be argued that independent validation may raise issues and patterns previously missed by the researcher. It also allows the opportunity to explain the thinking behind choices and the reasons for lines of enquiry (Horsburgh, 2004). Independent

validation may positively contribute to the reflexive process and the explication of forestructures allowing the researcher to submerge themselves deeper into thought about the emerging themes and explication of the influence of their own background, experiences and preconceptions. On consideration of the above debate I decided not to seek independent validation of themes. However, given that this project is part of my PhD studies I regularly discussed my interpretations with my academic supervisors. I believe that this ensured submersion into the phenomenon and gave me the opportunity to reflect upon and acknowledge my forestructures of understanding.

Another method of enhancing the rigour of theme development suggested in the literature is for participants to validate the themes. Maggs-Rapport (2001) suggested that interview transcripts should be validated by individual research participants. Koch (2006) suggests that asking participants to read and discuss the construction derived from the analysis may establish credibility of the findings. Todres and Wheeler (2001) also described participant validation of themes as an essential strategy to ensure rigour in the interpretation and analysis processes- the premise being that findings should resonate with the participants as recognisable and comprehensible as representative of their own experiences.

However, several problems exist with participant validation of themes. The researcher and the participant will have different perspectives of the study. The aim of the researcher is to conflate the accounts of all participants in order to obtain saturation of categories, shifting substantive situations to a more generalised and theoretical discussion of the underpinning concepts. Participants will, however, have a greater interest in their own substantive situation than in the abstract synthesis of their own accounts with those of others (Horsburgh 2003). Morse (1998)

argues that as theory is developed from a synthesis of the perspectives of a number of participants it is inappropriate to expect individual participants to have the ability to validate the findings of the research as a whole. Hagens *et al.* (2009) performed a study assessing the impact of participant transcript review and found that the potential advantages in terms of data quality and validation of themes, compared to the additional time and effort required were very few. Asking participants to validate the themes may have the benefit of making the researchers own preconceptions and input into data interpretation more explicit. Notwithstanding this advantage, on balance I decided not to get the participants to validate the themes generated.

Concreteness

De Witt and Ploeg (2006, Page 225) describe concreteness as firmly placing the research within the context of phenomenon and also linking with experiences in their lifeworld. This notion is akin to Van Manen's 'lived throughness'. Van Manen (1990, Page 39) discusses the process of 'orientating to the phenomenon'. Phenomenological inquirers should clarify the orientation of the phenomenon to both the researcher and the researched. Van Manen suggests that individuals will experience a phenomenon from their own vantage point and it is necessary to explicate this orientation. Therefore phenomenology is not just about deriving factual descriptions of the phenomenon or recollecting an experience, Van Manen asserts that one 'must recall the experience in such a way that the essential aspects, the meaning structures of this experience as lived through' (Van Manen 1990, Page 41). Van Manen is alluding to the both the ontic and ontological nature of phenomenology. In other words phenomenology is concerned with both the thing or entity and the meaning of being in relation to the thing or entity.

Both the ontic and ontological must be reflected within research findings. Benner (1994, Page 99) agrees and suggests that the phenomenon and its context frame the interpretive project. Madison (1988) suggests that consideration of the historical and cultural context or everyday life world of the authors work is essential in understanding the phenomenon. The design of the study has aimed to strongly orientate the phenomenon of technology into the context of ICU. Therefore technology has not been described as a unique entity but within the context of the participant's experiences in ICU.

Resonance and Actualisation

A principle that many phenomenologists subscribe to is resonance. Resonance is described as being the experience of feelings evoked in the reader upon reading the findings (de Witt and Ploeg 2006). Resonance is the extent to which the reader upon reading the research reports may empathise or identify with the findings. De Witt and Ploeg (2006) draw parallels with Van Manen's notion of epiphany (Van Manen 1990) who suggests that understanding leads to self-understanding. In other words, the research findings will be uniquely meaningful to the individual reader which leads to further understanding of the phenomenon. In turn this gives rise to actualisation. The notion of actualisation suggests that phenomenological interpretation does not end when a study is finished. Readers will continue to interpret findings in the future (de Witt and Ploeg 2006). Actualisation therefore encompasses the potential findings may have. As such there is no way of monitoring or recording either resonance or actualisation. So whilst being commonly cited expressions of rigour, they are by their nature, conjectural.

Ethical Considerations

Although permission from the Local Research Ethics Committee and Trust Research and Development Department to carry out this research was gained, there were several ethical issues, which required careful consideration throughout the research process. The following section explores the key ethical issues and the researcher's responsibilities towards all stakeholders.

Informed Consent

A key consideration when conducting research is to ensure informed consent. Traditionally informed consent endorses respect for autonomy and the right to self-determination of the individual (Miller and Boulton 2007). Whilst there is a consensus within the literature that informed consent to participate in a research study is a worthwhile activity in principle, there is considerable debate regarding what this means in practice (Green and Thorogood 2009).

Informed consent is the cornerstone of research ethics since the Nuremberg Trials post- World War 2 (Boulton and Parker 2007; Green and Thorogood 2009) and has evolved over a number of years in response to historical events and controversies such as the World Medical Associations Declaration of Helsinki (1964), Human Rights Declaration, and the Alderhey Inquiry. Such events have demanded that the responsibility for ensuring ethical conduct during research endeavours has evolved from an individual responsibility to a professional regulation. As a result procedures have been standardised and formalised into specific criteria and guidelines laid out by national and international research ethic committees and associations. Hoeyer et al (2005) suggest that increasing litigious nature of society has also contribute to the change to clear guidelines and rules in addition to pressure from funding bodies and external regulators. Miller and Boulton (2007) however, argue that there is a tension between standardised ethical procedures and the

complex nature of qualitative research. Ethical universalisation, as Miller and Boulton (2007) refer to it, does not adequately reflect or address the ethical concerns raised during qualitative research. Miller and Boulton (2007) and Boulton and Parker (2007) suggest that this is particularly true of informed consent. The section below aims to explore what is meant by informed consent, discuss the limitations of a standardised approach and discuss how this may be applied to this phenomenological study.

Homan (1991 p71) suggests that there are several key components of informed consent. The 'informed' element consists of both the pertinent information regarding the research study being disclosed to the patient and the ability of the participant to comprehend this information. Sufficient information was delivered to the potential participant about the purpose and nature of the proposed research within the participant information sheet and confirmed verbally where required. The benefits, risks and burdens were made explicit both verbally and in the written material. I ensured that there was time and opportunity for the potential participant to ask questions and answered all questions honestly and openly. Inherent to a qualitative interview approach is the conversational style. Individual lives and interactions between social individuals are uncertain and complex. Informed consent assumes, however that it is known exactly how the conversation will proceed. Research relationships however, do not necessarily comply with this model of interaction as it is impossible to predict the exact direction of the conversation (Hoeyer *et al.* 2005; Miller and Boulton 2007). Researchers may only inform participants of their research intention and potential topic areas and not of the direction that the research may actually take. It is important to recognize that each research encounter and the process of consent within that encounter will be unique. Miller and Boulton (2007) highlight this as a

limitation of the current standards for informed consent and argue that qualitative interviews should be guided by good ethical motives and the researcher's personal sense of responsibility.

The 'consent' element refers to the participants' ability to make a rational judgment and the freedom to make a decision voluntarily (Homan 1991). Neale (2009) highlights that in order for informed consent to be completely voluntary the participant must be free from coercion and the fear of jeopardy or retribution. The patient population under study were, by nature of their critical illness and potentially traumatic circumstances of their illness, vulnerable. Liamputtong (2007) suggests that gaining consent from vulnerable people requires special sensitivity. Vulnerable people such as those recovering from a traumatic event may feel disempowered and a degree of apathy. As such Liamputtong (2007) warns that participants may unthinkingly agree to participate. In particular Liamputtong (2007) lists anxiety, fatigue and chronic illness as conditions that may affect the participants understanding and ability to make a rationale decision. Review of the research literature reveals that these are all common problems associated with recovery from a critical illness or traumatic event.

Recent data protection laws and guidelines on coercion of participants require an independent gate keeper to approach the potential participants or after an initial invitation the researcher must wait for the potential participant to contact them to express interest. The onus is therefore on the participant to volunteer rather than the researcher to recruit. Miller and Boulton (2007) warn that this approach may lead to a protracted recruitment process. It may also lead to a limitation in the diversity of participants. Other researchers have documented that participation in research seems to attract a relatively limited section of the population- usually the white middle class (Miller and Boulton 2007; Kaibara 2010). This could lead to a highly selective pool

of participants. In addition, the use of gatekeepers, may infer links between the researcher and the organization within which the research is taking place. For example potential participants may have mistakenly thought that I was employed by the hospital. This may have led to reluctance to share certain information or may indeed have deterred potential participants from participating.

In order to minimize the risk of inadvertent coercion of the vulnerable participant, the follow-up clinic secretary acted as the independent gatekeeper and made the initial contact via letter and then telephone. Once in touch with the interested potential participant, I emphasized that they were free to choose whether or not they participated and emphasized that I would not have any direct or indirect involvement with their future care. Participants were given time from information delivery to consider their participation before a decision to participate needed to be made. Potential participants were encouraged to discuss their involvement with a significant other. The final decision to participate was made at the start of the interview. The participants' freedom to withdraw from the study at any time with no explanation was reiterated at this point.

In compliance with the requirements laid out by the Trust Research and Development department and the NHS Research Ethics Committee, participants were invited by a formal invitation letter with a standardized formatted information sheet. However, there are potentially some limitations to this standardised document. The information required to be included within the information sheet is very detailed and depending on the nature of the study may be quite complex. Some potential participants may not have the time or inclination to plough through all of this information. In addition, the formal nature of the documents and

formal language required to satisfy the ethics committee may not be inclusive to all potential participants. Some participants may not engage with or may find difficulty in reading a multipage document. The complex content of the information sheet may exclude those who have little confidence in their language skills or intellect. Many potential participants may feel as though they have nothing interesting to say, however, unless they contact the research team there is no mechanism for allaying their fears or reassuring them. The process may also exclude those of society (usually the vulnerable or less fortunate) who may be suspicious of bureaucratic practices such as forms, information sheets (Miller and Boulton 2007). It is recommended that informed consent is documented. Indeed, research ethics committees make very specific requirements with regards to the documenting of consent. However, Neale (2009) argues that specific documentation and signing of consent forms make the process legalistic and is therefore somehow contradictory to the climate of trust and the relationship of collaboration between the researcher and the researched. However, despite their potential limitations and in order to comply with ethic committee procedure, the standardised participant information sheet was utilised and the participants were asked to sign a consent form in this study.

Risks, burdens and benefits

Risks

The ethical principle of non-maleficence suggests that the researcher should do no harm in the course of their research. Non-maleficence is of particular concern when interviewing participants. Since the exact conversation is unpredictable, it is feasible that, in the course of the interview, participants will unveil personal feelings and experiences that are upsetting in some way. In order to minimise any such potential upset, I made the nature of the interview explicit both verbally and within the participant information sheet. I also emphasized to the potential

participant that their welfare takes priority over the research and if in the event they experience distress they can stop the interview. Where necessary, patients were encouraged to discuss any un-resolved issues with the critical care outreach practitioners who were present at the follow up clinic, their doctor or general practitioner.

An interview method necessitates a close and engaging relationship between the researcher and the participant in order to produce rich and insightful data. However, the close relationship may compromise the presumed distance required to ensure there is no coercion or fear of jeopardy or retribution if the participants were to withdraw from the study. Management of researcher power is therefore an important consideration within this study. As participants discussed their feelings, care was taken to ensure that interviews were carried out in a non-threatening and non-judgmental way. From the outset I made it clear that I am not an employee of the NHS trust in which their care has taken place. I emphasized that I would have no influence on their subsequent care and treatment.

Burdens

The interviews took place in hospital premises alongside their follow-up clinic appointment. The nature of the study required the participant to give up to an hour of their time. In order to minimize the burden on the participant's time, I made sure that the research interview was scheduled at a time convenient to them, either before or after their follow-up clinic appointment. Adequate time between clinic appointment and research interview was allowed for refreshments and comfort breaks. The additional parking costs may have been of concern to the participants, therefore I offered to reimburse the participant the additional car parking costs.

Benefits

Participants may find discussing their experiences of being a patient in ICU cathartic and may even help them to make sense of their journey. Participants may also derive some satisfaction in knowing that they are participating in a research study the results of which may contribute to the development of clinical practice in ICU.

Confidentiality

Once participants agreed to participate in the study, they were assigned a code number. The code number is only known to the researcher and the participant. All tape recordings and researcher notes were labelled with this code number and not the participants name to ensure confidentiality. Confidentiality was maintained throughout the research process with codes being ascribed to transcripts, tapes and notes. Care has been taken so that participants will not be identifiable from quotes used in any written report. All research materials have been stored in a locked filing cabinet, in a locked office for the duration of the project. All research materials will be stored for 10 years in a locked filing cabinet in a locked office after which time they will be shredded and destroyed.

Chapter 5: Findings

Introduction

The following chapter presents themes derived from the analysis of the participant interview data. Although the themes are introduced in discrete sections, they are more intertwined and convoluted than what is possible to present in writing. Presenting themes as discrete entities does not adequately portray the themes fluidity and interactions. The themes have no particular hierarchy as they all contribute equally but differently to the understanding of patients' experience of technology in ICU.

Participant quotations are utilised to substantiate the themes and, where they exist, illustrate deviations from the theme. I have been very conscious of adequately representing the participants' voice and not detracting from the essence of their accounts. Where necessary, some included quotations are long in order to include the contextual information to the participants account and to maintain authenticity. In contrast, other quotations have necessarily been edited to only include the relevant text to support the associated discussion. I have indicated where I have omitted text from the participant original account with a triple dot ellipsis (...). I have removed any details from the participants' accounts that may compromise anonymity and confidentiality of the participant, their relatives, the health care trust, and health care professionals. I have replaced these details with a generic description placed within square brackets ([description]). Whilst presenting the rich descriptions of participants' accounts I provide an accompanying commentary which explains the analyses and aims to provide the links between themes. Where appropriate I have included my pre-conceptions and reflexive notes from my research diary and field notes.

Population

The intensive care unit in which participants had been patients was a sixteen bedded general adult intensive care unit which provides critical care services for a large university hospital trust. The unit admits between 300-400 patients per year. The general adult intensive care unit provides care for level three patients. The Department of Health (2000, Page 10) define level three patients as 'Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure'. This particular unit admits both elective patients, usually after complex surgery, and emergency trauma, medical and surgical patients. The Hospital Trust under study has a separate neurology unit with its own level three care facilities. Participants were not recruited from the population of patients admitted to the neurology unit. Therefore the research population did not include patients with head injuries or other neurological conditions who required level three care. All patients who have been an inpatient for four or more days on ICU and have subsequently been discharged are invited to attend a critical care follow-up clinic. During the eighteen month period of data collection, 132 patients were invited to attend this clinic. Out of those invited only 83 patients attended. From these attendees, nineteen patients in total were recruited to participate in this study.

Participant Characteristics

Nineteen participants in total were interviewed either before or after their critical care follow-up clinic appointment. All interviews were conducted in a private office in the out-patients department of the hospital. Participants were asked to provide information on age, length of ICU stay and time since discharge from ICU. They were also asked what their understanding of the reasons for the ICU admission. The information in Table 1 is therefore based on the

participants self reported data rather than their medical records. As a result, some information is incomplete or estimated due to participants having unclear memories. In addition some participants were unable to articulate the exact diagnosis or symptoms that led them to ICU admission- some simply cited 'heart trouble' or 'my breathing'. According to the participants self reported data the average age of the participant is 57.5 years (+/-12.4 years) ranging from 32-86, the average length of ICU stay was 2.1 weeks (+/- 0.9 weeks) ranging from 1-4 weeks. The average time since discharge from ICU at interview was 4.3 months (+/- 0.8 months) and ranged from 3-7 months. A wide range of reasons for admission were cited. All participants were white and English.

Participant Number	Age (years)	Length of ICU stay (approx. weeks)	Time since discharge from ICU (months)	Patients self reported reason for admission to ICU
1	74	3	4	Pneumonia
2	86	1	4	Heart attack
3	45	1	6	Post-operative Infection
4	43	2	5	Car Accident
5	69	4	5	Unknown
6	57	2	5	Pneumonia
7	32	1	4	Infection
8	74	2	3	Post-operative
9	52	1	4	Seizures due to Lupus
10	55	2	4	Sepsis following a bone marrow transplant
11	37	3	7	Car accident
12	41	4	3	Pneumonia
13	68	1	5	Heart problems
14	67	4	4	Unknown
15	63	2	5	Car accident
16	76	2	4	Breathing problems
17	43	1	3	Pneumonia
18	58	3	3	Unknown
19	52	1	4	Post-operative

Table 1: Participant characteristics

Participant Memories

Many participants, either before or during their interview, suggested that they had few memories of ICU. Many apologised in advance as they felt that they didn't remember much about specific experiences.

'But I don't remember anything at the time or for possibly another couple of weeks. So when I got admitted, well I don't remember [hospital in the South of England] at all. And I'm pretty sure that I don't remember the first week I was in ICU. Because that was when my sister in law was there wasn't it? I don't remember her being there at all.' **(Participant 9 Lines 8-12)**

'I remember nothing to be quite truthful. I have no memory what so ever. And I don't remember anything in intensive care. Apparently I was awake, or I was conscious, I was talking but I've personally got no recollection of anything. There were things that I said to my family on the first couple of days that I don't remember at all. Um...I know I was air lifted here. Well actually I remember the paramedics asking me if I wanted to go to the [name of the hospital] and I said the [name of the hospital]. That's what I remember.' **(Participant 7 Lines 14-21)**

This response was not unexpected as from my previous clinical experience of seeing patients at follow up clinic, many patients demonstrated a poor memory of their experiences in ICU. Prior to data collection I was concerned that my participants would only have hazy or distorted memories of ICU. In order to overcome this I originally intended on interviewing up to 30-35 participants in order to ensure that I achieved data saturation however, all participants (including participants 7 and 9) despite testifying to the contrary, were able to clearly articulate memories and experiences, often in a great amount of detail. It would appear that participants

either remember far more than they think they are able or they think there is more to remember than there actually is. Arguably, the process of the interview may have jogged the participants' memory. Reflecting on the interviews, led me to believe that participants found the interview process therapeutic- in fact many stated that the process was cathartic.

Comparing my clinical experience of seeing patients in follow-up clinic and conducting a research interview there is great variance in patients reported memories accounts of their experiences. It was apparent that participants within the research interview described their experiences in greater detail than I had previously experienced during follow-up clinic. In addition the patient accounts during the research interview included both positive and negative experiences, whereas during follow-up clinic patients appeared to be more positive. This might be explained by the different format and intention of a follow-up clinic appointment and a research interview. A follow-up clinic appointment has a clear agenda, follows a structured format, often using a standardised assessment *pro forma* and is for an allotted time period. In addition, the follow-up clinic is facilitated by a variety of health care professionals all of whom will have actively contributed to the care of the patient. In contrast the semi-structured interview approach let the participant set the agenda. I encouraged participants to tell their story in their own words at their own pace. There was no time restraint employed. I was external to their experiences and had no connection to their care or the hospital trust. Therefore it is possible that participants were perhaps more open about their experiences.

Introduction to the themes

Themes derived from participant accounts were complex and convoluted. Participants described their experiences of ICU within the general context of ICU. Often their experiences of technology

were inseparable from their experiences of being critically ill in ICU which reflects how intertwined technology is with the context in which it exists. It is clear that patients perceive technology as being integral to the environment of ICU, their care, their treatment and recovery. Analysis of participants accounts indicate that technology influences the physical environment in which they find themselves, their sensory perceptions, their social interactions and the organisation and delivery of the care they receive.

Experiences of technology have been described in several key themes: My Useless Body, Making Sense of It, and Technology and Care. My Useless Body describes the physical ramifications of their critical illness and technologies associated with their care. Making Sense of It describes how participants rationalise their experiences of technology and also describes how they coped with their experiences. Technology and Care describes the participants' experiences of being cared for in a technological environment and also describes their perceived role of health care professionals.

In addition to the three key themes identified there are two ubiquitous threads that flow through every theme. These are temporality and agency. Temporality refers to the notion that participants' perceptions of technology and their experiences of being critically ill change over time. Agency refers to the participants' capacity to make and enact choice. It is evident that there is a varying amount of agency related to the participants' stage of illness and recovery with it continually oscillating along a continuum. During the description of the key themes I will highlight temporality and agency. Figure 1 provides a schema of patients' experiences of technology.

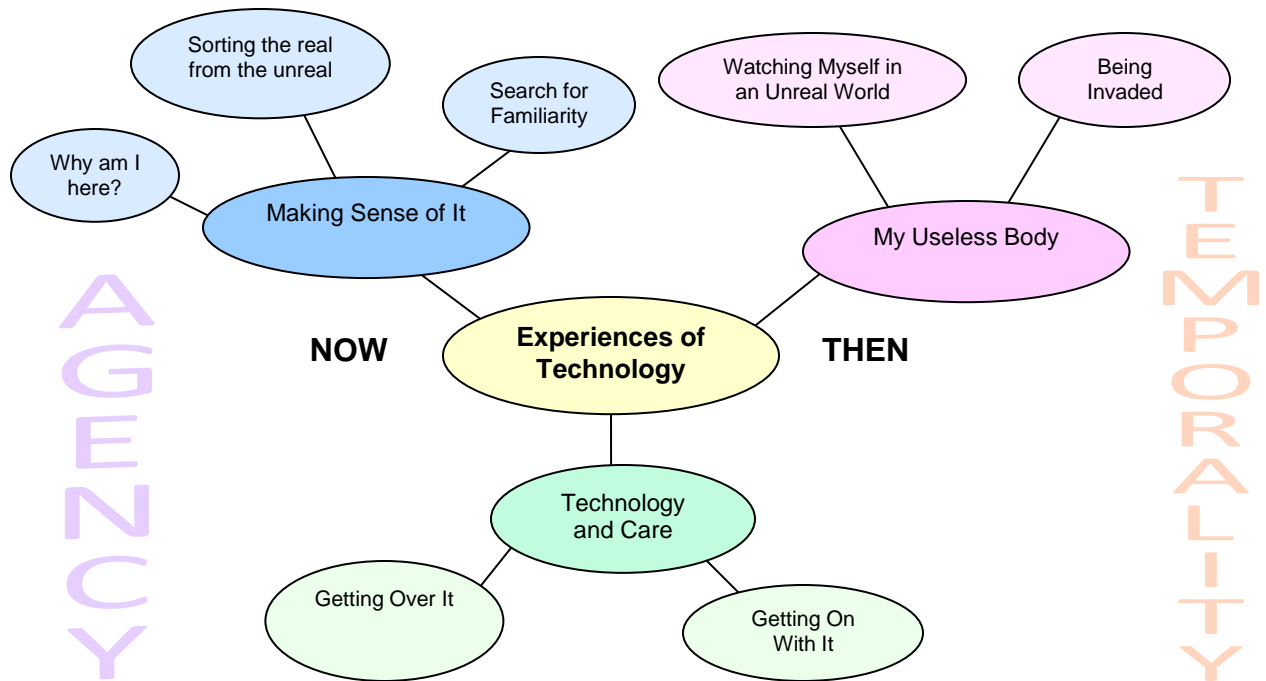


Figure 1: Schema of Patients' Experiences of Technology

My Useless Body

'Oh, I couldn't do anything. No matter how hard I tried, I couldn't move, breathe properly, talk, eat, drink...you name it. Everything was just so... well my body was useless' (Participant 3 Line 54)

A key issue for all participants were the physical ramifications of their critical illness. The theme of 'My Useless Body' describes the patients' perceptions of their body and physical self in relation to technology and the care they receive. Many participants define their time within ICU in terms of their failing body and the interventions and technologies used in their care and treatment. In particular participants' described the impaired function of their body and described how technology supported or performed functions that their bodies would ordinarily

do. These functional deficits were either as a result of their critical illness or as a result of the technologies utilised in their treatment and care. This theme sets the context of how the participants experienced technology and their care.

When asked what had led to their admission to ICU, all participants, although not necessarily having a personal memory of the events or knowing the exact diagnosis, had a clear idea of the physical reasons that had led to their ICU admission. Participants were often dispassionate when describing their illness- many reeled off a list of ailments as though they were reading a laundry list:

'Oh right, OK. I had ten ribs broken, sternum broken umm, crushed foot, wrist, cheek bone broken umm lip, cut lip, eye, puncture wound in my shin. Broken ankle... But my main problem was that I had a lacerated liver which wasn't apparent at the time. And when they spotted this internal bleeding I had and then I had a collapsed lung and all sorts of other problems. It was apparently affecting my heart too, because of the pressure. Anyway, because of all that I basically ended up in quite a state.' **(Participant 4 Lines 20-32)**

'Well I had my oesophagus removed due to a tumour and that led me to ICU for the first time. The second time my stomach collapsed so they had to remove it and connect it to my colon. I ended up having three ops. The third one that was the big one, when my lung collapsed... Apparently my lungs, heart, and kidneys weren't working. That is why I had to go on life support'. **(Participant 3 Lines 14-22)**

In the process of describing their experiences, some participants expressed despair at the dysfunction of basic body processes. The bodily disruption appeared to represent an inability to exert control over their bodies.

'They gave me a notepad and pen to write on but I couldn't even hold the pen. Something so simple! Can you imagine! I didn't realise I was so weak, I literally couldn't do anything.'

(Participant 4, Lines 67-68)

Breathing in particular seemed to evoke the most surprise and frustration:

'I mean I was on that machine, I remember that- the one that helps you breathe. I remember thinking that I would be better off without it. It was bad enough that I couldn't move my legs or arms so I mean surely I could breathe by myself?' **(Participant 14 Lines 452-454)**

Other participants expressed concern and frustration that their limbs were weakened, especially when they perceived nothing specific to be wrong with them:

'My arms just wouldn't work. It was like I just couldn't control them. I had no strength you see, and I couldn't seem to control the muscles. Something so easy too. Talk about frustrating- especially as there was essentially nothing wrong with my arms' **(Participant 16 Lines 165-167)**

'There was one other clear bit where I wanted to stand up, I really wanted to stand up and this guy said to me, 'You can't stand up! When was the last time you stood up? You can't stand up on your own!' For me at that point, I just thought well how ridiculous, of course I can stand up, I

don't need help standing up. And the way my brain interpreted it was that I don't rely on people to help me stand up, I can stand up myself, I mean I am not that lazy. It was just totally ridiculous. And of course I couldn't stand up; I hadn't been out of bed for three weeks.'

(Participant 12 Lines 138-140)

The dysfunction of the participants' body appeared to dominate the descriptions of their experiences of ICU.

'Everything was a massive effort. I couldn't do anything easily. Just moving my hand took all of my energy and concentration. Honestly, that was the main thing I remember was the effort even the simplest things took. Nothing was easy. It was a nightmare...That's all I could think about was how hard everything was...' **(Participant 18 Lines 109-112)**

'I needed help with everything. I mean they gave me this yoghurt to eat but I couldn't hold the spoon. So it just sat there until... well, they had to do it for me. I couldn't even brush my hair. I couldn't do anything. I kept thinking that I must try, I must try but I just couldn't. It was so frustrating' **(Participant 1 Lines 547-550)**

My Useless Body not only relates to the physical body and its mechanical function but also incorporates the psychosocial ramifications associated with its dysfunction. As is evident from the description of this theme, most significant is the lack of personal agency which frames the participants' perceptions of their Useless Body. Participants further characterised their 'Useless Body' by describing it in terms of the following sub themes: Being Invaded and Watching Myself

in an Unreal World. The following section explores these themes in more detail. Below is a conceptual schema depicting the interrelationship of these themes:

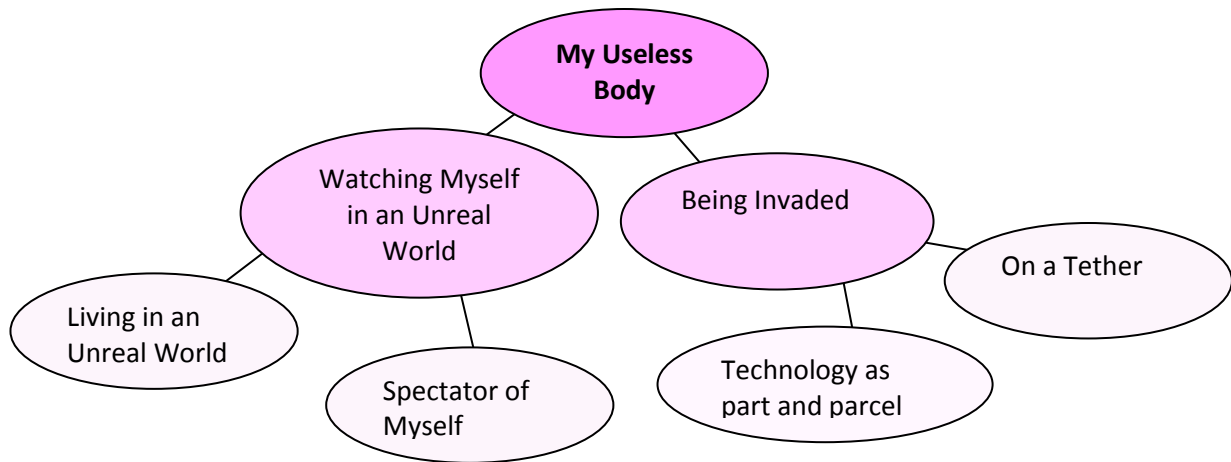


Figure 2: Schema of My Useless Body

Being Invaded

Of clear significance to participants was not necessarily the injury or illness which led to their admission to ICU- as seen above, these injuries were often described with acceptance and stoicism. However, the injuries or traumas as part of their treatment or care seemed to cause far more anguish. Frequently the enforced injuries or traumas involved technology such as endotracheal tubes, tracheostomy tubes, intravenous access devices, and nasogastric tubes.

'Oh and they put this naso tube [nasogastric tube] in which was draining my stomach. So basically I could see everything coming out of my stomach. It was disgusting...horrible. It was like I was falling apart' (Participant 11 Line 69-74)

Participant 4 gave insight into why enforced injuries might be so significant to patients in ICU by suggesting that the tracheostomy was something that was deliberately done to them.

'But the trachy, everything else was secondary to that yet that was something that they did to me. All my injuries were secondary in my mind. I suppose that is it, the accident was just that, but this was a deliberate injury so it was harder to cope with. And of course it is a constant reminder that it is there.' **(Participant 4 Lines 238-241)**

Other participants described interventions as something that was done to them inferring a lack of choice and lack of control. Participant 14 described their arterial line:

'And again I felt that this was something that they had done to me. Somehow, I felt guilty that I was causing trouble, yet really it was them that had put this drip in, in the first place. The thing was I didn't even know what it was for.' **(Participant 14 Lines 132-135)**

Participant 16 described their tracheostomy:

'This is why for ages I couldn't understand why they had done this to me. I honestly believed that I could breathe better on my own! If anything it felt as though the trachy and the vent were hampering me. I remember trying to explain this to the nurse.' **(Participant 16 Lines 140-143)**

Participant 5 describes as a result of complex surgery how the resulting oesophageal drainage bag was an invasion to their body. The participants' feelings of helplessness are again demonstrated through the expression of 'how could they do this to me?'

'The stomach had collapsed after the first op. So they removed the stomach and put uhhh a pipe in from my throat, the back of the throat down to uhhh, a colostomy type bag on my chest so that everything I swallowed went into the bag. Umm and then they fed me through the tube in the duodenum. I forgot the name of it . Anyway, yes so that was the next op.' **(Participant 5)**

'How did all of that feel?' **(Me)**

'Well I felt a bit invaded. It was weird being able to drink but seeing it all go into the bag. At the time I just put up with it but thinking back on it, it was quite disgusting really. I mean, how could they do this to me? I just remember feeling that I wasn't in control of my functions- everything was going wrong and not working properly.' **(Participant 5 Lines 106-120)**

Participants appear to accept their critical illness due to its sometimes serendipitous nature whereas they had difficulty accepting the injuries caused by technological interventions which they view as being deliberate and planned and, as described by participant 5, feeling 'invaded'. In addition the enforced injuries are frequently external to the body, visible and tangible whereas the precipitating injury or illnesses are inside the body, hidden and often indistinct.

Many participants described clear memories of the endotracheal tube (ET tube) and ventilation, whilst some participants had no memories of intubation or ventilation. I was surprised at the number of participants who could remember having an ET tube in place and being ventilated as in order to tolerate the ET tube, patients are usually well sedated. It is generally assumed in practice that most patients will have no specific memory of this intervention. Certainly, whilst reflecting on my own pre-suppositions and own experiences of caring for critically ill patients in ICU, I assumed that patients would remember very little about intubation and ventilation. I also

assumed that what little memories the patient may have would be very hazy and probably distorted. However, it is evident that these preconceptions were not supported by the findings.

Participant 3 described clear memories of their ET tube as being particularly traumatic:

'...and I found that I had something in my throat and I couldn't work out what it was. I felt gagged. I must say I did wonder at first if I had been kidnapped by terrorists! The nurses kept pulling at it- I didn't know what they were doing. But I could feel it in my throat.' **(Participant 3 Lines 60-63)**

Many participants expressed annoyance and discomfort at the ET tube and some indicated that at the time they did not understand the rationale for its insertion.

'I know my throat felt really restricted. I don't know if it was that tube they had put in. You know when you have tonsillitis, and your throat feels scratchy- it is like that but worse. It is like having a massive frog in your throat. But it felt like that for ages, even after the tube had come out' **(Participant 13 Lines 67-72)**

Interestingly, participant 12 appeared to understand the intended purpose of ventilation but at the time, didn't feel as though it was helping.

'Umm obviously I don't remember it going in or anything like that but I remember waking up with it. It is a horrible, horrible thing. It is extremely hard to appreciate how it's helping you even though it quite obviously is. Because you can't really feel the air going in, you can hear the air

but you can't really feel it. You can't feel it pushing your lungs up and down. Or at least I couldn't. So my overwhelming sense was that I could do this myself, which clearly I couldn't.'

(Participant 12 Lines 160-164)

From some of the participants' narrative it is clear they perceived 'injuries' or interventions forced upon them but many are unclear as to the reasons why. Some patients with the benefit of hindsight and subsequent explanation could rationalise why they had an intervention. This represents the temporal nature of participants' perceptions:

'Well of course I couldn't breathe without the ventilator and the trachy... At the time I couldn't understand it but now I understand. I mean I would have died unless they put the trachy in...They told me that!' **(Participant 13 Lines 52-53)**

'It was more confusion than anything else. Now I realise that it [the tracheostomy] was totally necessary and quite frankly I would have died without it and there is no way that I could have breathed on my own, without that help. But at the time, I really felt that they had done this awful, horrid thing to me and I couldn't understand why. I guess that is the paranoia from the drugs.' **(Participant 17 Lines 679-683)**

Even with the benefit of hindsight some participants are unable to make sense of the purpose of interventions. Participant 2 described the central venous catheter as a 'bolt in his neck'.

'It was the weekend and the nurse came on and I asked her what has been happening, what has happened to me? I've got a bolt in my neck for something what is that for? I felt a little bit upset

about it. And then the Doctor was coming and doing his rounds and I said, well I said to him about it, I'd like just a bit of information, I said I should like to know what went on, what happened? I haven't got a clue what has happened and I should like to know. Well of course he told me eventually. And I said, 'What is this in my neck?' And he said well we had to make a decision because you weren't capable of making decisions so we had to make a decision. So I said, what is it for? And he said that it was a commercial thing. I said do I have to have it and he said, Oh no, not if you don't want it. I don't know if there is a mark there? Is there? Can you see a mark?' (Participant 2 Lines 206-219)

Many participants focussed on the discomfort and pain of enforced procedures such as intubation, cannulation, nasogastric tubes. Few described pain of injuries or as a result of their illness which led to their admission. One particular participant who had multiple injuries resulting from a road traffic collision including a shattered pelvis, multiple rib fractures, and a crush injury to their leg did not mention throughout the duration of the interview mention any pain or discomfort resulting from these injuries but described in detail, without prompting, the discomfort of the nasogastric tube:

'I don't know where to start... that nose tube was just awful. If I could have got rid of that my time in ICU would have been so much more tolerable. I mean it was just a constant irritation. First of all it was constantly in my line of sight. So I couldn't even open my eyes without seeing it. Then I could feel the tape pulling on my nose, so the skin had become quite sore and it was like having a permanently blocked nose. Every time I moved it made my eyes water, it was awful. When they put things down it I could feel it really cold, going into my stomach. Sometimes it was so cold it gave me a headache. I was so glad when they said that it could come out. I said to

[partner], and he told me to stop being so silly, but I said to him at the time that I would rather starve to death than have that back in. And I meant it...' (Participant 7 Lines 98-107)

Another participant described the discomfort of the central venous catheter:

'...It just pulled and tugged all the time. It was like having a bee sting or something in your neck...It was quite funny because, even my husband said, he said that he thought the surgery would be more painful. Because I'd got stitches all the way up here [points to chest], well those staple things they used... But, yes, it was that blimmin' line in my neck that I moaned about! [laughter]' (Participant 18 Lines 73-78)

Participants appeared to focus on enforced injuries such as intravenous cannula, nasogastric tubes which in essence are the small tangible distresses and irritations, perhaps because the bigger picture is too big to rationalise and comprehend. The overall essence of the participants' accounts suggests that they often could not make sense of the interventions and technology at the time. Even with the benefit of hindsight and rationalisation many participants may know the reasons behind the interventions but do not necessarily demonstrate a deep understanding. As is demonstrated within the above quotations, participants often only understood the enforced injuries in terms of life or death- 'I would have died without it'. This in most cases was possibly true, however this definitive statement, almost erects a barrier to further reflection. It seemed that participant did not see any further reason to rationalise the presence of the technologies and enforced interventions, as the choice of life over death was reason enough.

On a tether

Participants described how interventions and technologies often reduced their mobility and reduced their independence. Within this theme technology is reflected as an externalisation of agency where participants described themselves as being passive and surrendering their agency to technology. Participant 12 described the enforced immobility as a result of having a tracheostomy as feeling like a tether:

'And I think the worse part or more importantly it feels like a tether. It feels like you are attached to, well it's a very sensitive part of your body and it feels like you are attached, like a dog on a lead. So you are attached to this machine and you like twist there and there is a little pull and you move here and there is another pull. So you are basically you can't move. And it well at best it tickles you and at worst it is really uncomfortable.' **(Participant 12 Lines 169-173)**

Other participants described feelings of restricted movement:

'I remember it tugging. I had this wire around my neck you see so it used to tug when I moved. It was like a noose. It kept me awake all night. I used to lay looking at the ceiling.' **(Participant 3 Lines 11-12)**

'I'd feel myself being pulled this way and that but it was like being a puppet on a string...' **(Participant 5 Lines 57-59)**

The choice of metaphors used to illustrate the feelings of enforced immobility, tethered, like a noose, a puppet on a string, all infer a lack of choice and feelings of oppression. It is significant

that participant 12 likens their feelings with that of an animal inferring that they felt dehumanised, and having a loss of control.

Often participants described their restricted movement as not being a physical inability to move but as a result of the health care professionals and or the equipment:

'I just felt like my hand wasn't my own as I couldn't move it in the way I wanted to. If I did, the nurses would come and move it back again. I mean they were only doing their job. But at the time I didn't understand why.' **(Participant 8 Lines 87-89)**

It is interesting that participant 8 emphasised that nurses were only doing their job which suggests that if it wasn't considered as part of their job that it would be somehow unacceptable. In other words all of their movement was controlled by the nurses. Another participant described how their movement was dictated by the alarms that went off as a result of disturbing their arterial line:

'Those alarms! That bleeping! So I was like, putting my hand up here and down there and then over here. Anything to try and stop this thing from bleeping. But it didn't no... nothing worked.' **(Participant 14 Lines 90-92)**

One participant described this as being a 'slave to the environment':

'I was hooked up to God knows what. I couldn't even lift a spoon to my lips, even if I wanted to. I felt a slave to my environment.' **(Participant 4 Lines 446-448)**

Some participants described the hospital bed itself as restraining them:

'I started to realise that I can't move this and I can't do that...I know my throat felt really restricted. I don't know if that was after the tube had been taken out or if the tube was still in. I mean you do feel as though you are trapped in a little bit of a way. I mean everything happens on the bed- even going to the toilet! My world began and ended on that bed. So yes it made me feel trapped. I just wanted to be anywhere other than where I was. (Participant 7 Lines 234-239)

'I do remember feeling as though my lungs were being compressed. I remember that because at first I thought it was something to do with the bed... It was one of those flotation beds. It wasn't a standard bed that you lie on top of, so it shrouds you so that you feel inside it.' (Participant 8 Lines 102-105)

Technology as Part and Parcel

Whilst many participants described the intrusion of technology and interventions, some participants described instances where the technology became subsumed into themselves:

'I wasn't perturbed by anything that was there...It just became part and parcel. Like the dialysis machine, it was just there. It became part of me...' (Participant 2 Lines 182-184)

'The wound was quite bad. They actually put me on a vacuum dressing for that, umm I was connected up to that. So when I was trying to do my exercises I had to carry a little bag with me. I got used to it though so I didn't mind ...It just became part of me.' (Participant 3 Lines 279-285)

Some participants described how they had difficulty distinguishing between their own body, the technology and the symptoms of their illness:

'Uhh the ventilator alarm...I was convinced that that was part of the illness. So whenever I heard that I was convinced that it was an airborne disease that was living in the vent and that when you, when you coughed the alarm went off, but in my head it was part of the illness. The thing living in the ventilator was the illness and it is that that is making that noise and you are making it make that noise because of the coughing and you are ill and it is feeding off you. It sounds crazy.' **(Participant 6 Lines 117-122)**

'But the funny thing was I had chest drains from the surgery which I didn't even realise. I mean I couldn't feel them at all. It was weird because I was aware of the bottles on the floor and the tubing but I didn't think they were attached to me! It was only when the nurses said that they needed to take the drains out and I was like 'out of where?' I honestly didn't think that they were inside of my chest! I didn't know where I thought they were going but if you had asked me I would never have guessed that they were actually inside my chest!' **(Participant 13 Lines 49-58)**

Participant 8 described how they had become so accustomed to non invasive ventilation technology that they missed it when it was gone.

'I remember it forcing the air in and although it was a relief, quite a big relief as it was helping my breathing, it was rather unpleasant. At first it was disorientating I just wanted to take it off as I felt that I was fighting against it but then once I settled into it was a comfort. Eventually I

almost forgot it was there. When I eventually got rid of it for good I almost felt naked, like something was missing [laughter].' **(Participant 8 Lines 59-64)**

Throughout the theme Being Invaded, the participants accounts are very physically orientated describing the physical sensations, deficits, and restrictions. However despite being physically orientated in their descriptions the participants indicate a clear lack of agency. Descriptions of 'Being invaded', 'On a tether' could just as easily reflect the participants' psychosocial and emotional experiences. This is further characterised upon consideration of the next theme 'Watching myself in an unreal world' where participants describe the psychosocial impact of their Useless Body.

Watching Myself in an Unreal World

'Watching Myself in an Unreal World' describes the more metaphysical aspects of the Useless Body. Many participants described feelings of being disconnected from their body, the environment and their experiences. Participants suggested that their conscious thoughts did not necessarily correspond with either their physical self, or their emotions and behaviours, as though there was a disruption between the integration of mind and body.

Spectator of Myself

Participants frequently described periods of their stay in ICU as though they were a spectator of themselves. Participants described a disconnection of their physical self with their mental self such that they described feeling as though they were characters within a book, play or movie:

'...and I remember imagining different stories...I almost felt like I was a character within a book. Weird, like I was watching myself in a play or something and I kept imagining different endings...' **(Participant 5 Lines 434-436)**

'When I think back on my experiences it is like watching a movie. I can't imagine being in that situation myself... I know that I was in a bad way as I have lost a lot of weight and I was very weak at first but had it not been for that... I would be convinced that I had woken up from a bad dream.' **(Participant 17 Lines 104-109)**

At the same time participants described having little or no control over their situation.

'I had absolutely no control over it. So there I was almost watching myself playing out a scene, like on the telly or something. But I had no control over my body or anything. So I'd watch myself and think, well I want to do this but I couldn't, I couldn't move or anything' **(Participant 18 Lines 169-173)**

Some participants described feeling divorced from their personal physicality almost as though they were experiencing their own body from an objective view point. Participant 6 even described physical sensations as not belonging to them:

'Well, I know this is going to sound weird, but as I was laid there, laid flat on that bed it was like I was looking at somebody else...Even my skin didn't feel like my own. When my husband used to come in and hold my hand, I thought he was holding somebody else's. I almost asked him,

'Whose hand are you holding?' Before I realised that it was mine. I could see it, I could move it yet still it didn't feel like it belonged to me.' **(Participant 6 Lines 103-108)**

Participants also described being disconnected from their own emotions and behaviours as though they did not belong to them.

'Well I remember getting really angry with that nurse. I feel awful about it now, remembering it, I am really embarrassed because I am not an angry person. My husband will tell you, I don't say boo to a goose. But here I was shouting at this nurse because as far as I was concerned she was keeping me prisoner in that bed and all I wanted to do was get out. I mean I never get angry. It was like it was somebody else. I'm horrified when I think what I said to her...' **(Participant 19 Lines 126-131)**

'I've always been calm and don't let things bother me but in there, I couldn't help it! I just got so upset about it all, the slightest thing and I was off. I couldn't control it.' **(Participant 14 Lines 46-47)**

Participant 18 described periods where she behaved uncharacteristically during her time in ICU and expresses astonishment and embarrassment when reminiscing about her behaviour:

'I remember a really weird thing happening. I remember seeing my two children standing there and a Doctor, because it must have resonated somewhere, because the Doctor said to my children 'your mother is a tough woman' and I started singing at the top of my voice 'I am invincible, I am woman'. I mean I can't sing, I don't sing, I didn't even know that I knew the words.

And I sang from then on, [daughter] said 'Sweet dreams' one evening and I started singing 'Sweet dreams are made of these' You know by the Eurhythmics? I mean, what must they think? Why did I do this? It wasn't me... it can't have been' **(Participant 16 Lines 80-85)**

Likewise, participant 16 described behaving in way uncharacteristic to her normal self:

'I remember pulling something out, I think it was the catheter going in my nose. But yes I remember pulling it out. The funny thing is I knew exactly what I was doing... It was irritating me so much, I started pulling at it, and it hurt, but for some weird reason I just continued. Even though I knew what I was doing was wrong and totally unlike me. I guess I was just so fed up.'
(Participant 16 Lines 145-149)

Participants described being socially disconnected. Most frequently participants described this in terms of a lack of effective communication. Communication that occurred was often described as being one sided; staff and visitors might talk to them but they would not necessarily be able to respond in the normal way. The lack of communication was frequently attributed to technology.

'Well, I just got used to it. I didn't understand why I couldn't talk. That was the thing. Just this damned dry mouth. I kept thinking if only I could have a sip of drink I would be able to talk. Of course the tube in my mouth would have stopped me anyway!' **(Participant 2 Lines 41-46)**

'It was hard because all of the machines, my husband had to sit to the side and reach over the bed to even touch me. I couldn't see him properly. So I found it hard to talk to him properly because I couldn't see his face.' **(Participant 6 Lines 80-83)**

Participants particularly expressed frustration at not being able to verbally communicate with their relatives and being unable to write.

'...and I couldn't hear. This was, so not being able to hear or talk I did feel that I wanted to say things to [husband] and I... He tried to put a pen in my hand, after a day or two they found a pad but I couldn't even hold the pen. And it was quite a few days before I could write a few words that were legible' **(Participant 1 Lines 183-186)**

'Umm, I'd been laid in intensive care for so long obviously my motor skills weren't very good. So I couldn't write. My first recollection of the real world was my husband and brother and me trying to talk to them. I couldn't talk, well, I couldn't write. It was very frustrating I tried to write and it was all over the place...Then they got me this board with the letters on! Well I couldn't even get my fingers to point to the right letters. That did upset me, I've got to say.' **(Participant 4 Lines 170-177)**

Participant 7 suggested that verbal communication was less important to her but really valued physical contact.

'It didn't bother me that much- the fact that I couldn't talk. I was just so pleased to see my husband and to see my family. And it was more physical, you know like holding hands? It was the

more physical side of it and somebody touch you or give you a bit of a squeeze on the arm or something. It was more the physical comfort that was of value rather than the talking. So it didn't bother me too much.' **(Participant 7 Lines 142-146)**

Conversely other participants, however, described how they were unable to engage in normal affection and touch which they directly attributed to the presence of technology:

'Oh yes there were tubes everywhere... I had one in my mouth' **(Participant 1)**

'And how did that feel?' **(Me)**

'Well it was a little bit difficult to kiss [husband] goodbye! [Laughter]' **(Participant 1 Lines 104-112)**

'What would have been really nice is having a big hug but that was impossible with all the paraphernalia! [laughter]' **(Participant 8 Lines 256-257)**

Many participants described difficulties in communicating with staff working on ICU.

'...because I don't remember being able to talk still. I remember trying but the sound just wouldn't come. I remember trying to shout out to one of the nurses and no noise came out. She just carried on walking by.' **(Participant 6 Lines 198-201)**

'I did find it quite frustrating not being able to communicate with the nurses, when they came in and when you tried to say something it was like the guessing game. They were trying to work out what I was saying!' **(Participant 10 Lines 68-70)**

Participants describe how this lack of communication led to feelings of social isolation and detachment.

'Well I was trying to tell them that I needed more oxygen, I mean couldn't breathe at all. So I kept trying to tell them but of course with the tube in my mouth I couldn't make any sound. So it got to the stage where I couldn't do anything. I was on my own, they wouldn't help me so I just gave up. I just felt out of it.' **(Participant 15 Lines 343-348)**

'But yeah that was not very nice that I couldn't communicate. I remember one instance in [hospital]. I wanted the nurse for something and of course the nurses are buzzing around you all the time. But in this instance they were nowhere near. I can't remember what I wanted, but the fact that I couldn't shout anybody. That got me tears pricking at my eyes because I'm thinking come on somebody.' **(Participant 4 Lines 184-188)**

Living in an unreal world

As well as feeling physically, emotionally and socially disconnected, participants also described feeling disassociated from the environment and their experiences. Many participants described their experiences as being unreal or surreal.

'I felt just separated from it, I didn't know what was going on and the person that they were discussing the person attached to the machines wasn't me, like it was somebody else. It was like being in a world that wasn't real' **(Participant 6 Lines 76-79)**

Participants described a distorted external world. Many described people, events or objects that in their rational mind knew they could not have existed but at the time were very vivid. Participant 17 described how he believed that instead of being in a hospital, he was in his caravan:

'Well I thought that I was in my caravan and there was, this is the weird bit, I was being treated, I appreciated in parts that I was being treated by medical people, but it was in my caravan which was attached to the main hospital... And I couldn't understand why the caravan, why it isn't where I store it usually. And in moments of lucidity I kept saying to my wife, 'we must move the caravan back' (Participant 17 Lines 6-10)

Another participant described how they imagined a wall that moved:

'Well it was strange because just to my left I could see the wall and it was a proper wall, it had posters on and everything, but it was leaning in towards me and it seemed to get closer and closer to me. At times I felt that I would have been able to reach out and touch it. But then other times it was far away.' (Participant 15 Lines 182-185)

Other participants perceived every day, real objects as something else:

'I was convinced that the area opposite was dealing with black people and I could see lots of Black art and carved heads and that, I am assured now, are the drips and bits of equipment but I could see them very clearly. They changed each day.' (Participant 16 Lines 66-70)

'I remember a funny thing- I could see this urn on a shelf to my left, an antique urn. There probably was something over there, although I don't know what. But I clearly remember seeing this antique urn. I remember saying to the nurse that she needed to look after it, don't let them take it away as it is worth a lot of money, you know? It was over on the right hand side, on a shelf. To this day I don't know what it was. I can't make sense of it though. I just remember thinking that it was really important and I had to look after it.' **(Participant 5 Lines 180-188)**

Some participants remember seeing unexpected objects in their environment and trying to rationalise their presence.

'I do remember that there was a bed next to me where somebody had died and there was Indian feathers like a head dress hanging just above the bed. There was also music, like that pan pipe music. Yet there couldn't have been! Not in the hospital! I remember thinking at the time...' **(Participant 8 177-183)**

Others described distortions in the people they saw and with whom they interacted:

'I felt that they were dealing with a lot of street people as, I could see in the area opposite, they were making beds for all of them on the floor' **(Participant 17 Lines 17-18)**

'I remember seeing a lot of people walking around that were a different colour from normal. They were brown, but not like a black person but you know when you shut your eyes and squint and everything was dark and they were small too, like tiny little people.' **(Participant 15 Lines 4-5)**

Some participants even distorted the appearance of their loved ones or people with whom they would be very familiar:

'.....And the next thing I remember is [wife] coming in and saying 'Hello' and she had these funny glasses on. Although they are the same ones as she is wearing now, but the first thing I noticed was that they had enormous orange frames! And my son was the same. And I thought to myself, well I can see who it is but my wife hasn't got glasses like that and nor has [son], he doesn't even need glasses.' **(Participant 2 Lines 17-21)**

Again, some participants attempted to rationalise their distorted perceptions:

'Umm I can remember believing that one of the nurses was the poet Benjamin Zephaniah. I was convinced that it was Benjamin Zephaniah and I wanted his autograph but he kept telling me that he wasn't Benjamin Zephaniah. But I knew he was and was working their voluntarily. But then I thought why would a famous poet like Benjamin Zephaniah be working in ICU?' **(Participant 16 Lines 63-66)**

Participant 5 described a very disturbing experience of thinking that there was a fire within the ICU. It demonstrates that these altered perceptions affected not only his sight but also his sense of smell and hearing:

'The worse thing was one night I got this impression that the ceiling was full of smoke and I even grabbed one of the doctors and said to him to call the fire brigade... The smoke though was so

stifling. I genuinely believed that I could see it and smell it and everything. So, so vivid... I remember at the time being terrified. I felt that absolute fear; I really thought the place was on fire, I can still feel the feeling of suffocation... I was panicking but everybody else didn't notice. They were dawdling around as though nothing was going, nothing was wrong, but in my mind we were all about to die. I couldn't understand why they didn't care.' **(Participant 5 Lines 191-198)**

Many participants described having hallucinations

'I can remember that there were puppies were running all over the place, black puppies and tan coloured puppies and I remember being very frustrated that people didn't believe me. I could see their legs underneath the curtains and because nobody else seemed bothered.' **(Participant 16 Lines 56-58)**

Frequently participants' hallucinations and delusions were of a persecutory nature with many describing feeling as though there was a conspiracy:

'And the way they moved things around was with sheets of bubble wrap. This was all secret technology that only they knew about. And I kept thinking that I shouldn't be seeing it. And I wanted to tell them, its OK I am in the RAF [Royal Airforce] and I have signed the official secrets act so I won't tell anybody. But I really felt as though it was all secret and I was part of big conspiracy.' **(Participant 17 Lines 10-14)**

'I was convinced that I was going to be arrested. I just remember the staff moving bits of equipment around and I was convinced that it was to make room for a police car to come in and take me away. I thought they were going to arrest me for wasting hospital time! [laughter]. Yes wasting time. That was what was going to be on the front page of the newspapers...I felt as though I didn't deserve to be there, that I shouldn't be there... I had to be punished I suppose so therefore the police were going to come and get me.' **(Participant 8 Lines 118-124)**

In particular, participants described feeling as though staff within ICU were trying to harm them and described the surrounding technologies as instruments of harm:

'And the paranoia continued, my husband, for two or three nights had to sit up with me because I was convinced that one of the nurses was trying to harm me. When she came towards me with whatever...like medicines or she was fiddling with the machine I thought, right this is it. She is killing me' **(Participant 19 Lines 134-137)**

'I felt as though the staff were deliberately withholding the oxygen. I even said, Look I will pay for more, I can afford it and everything. Yeah, weird, at first I really thought it was a conspiracy and were deliberately teasing me with some oxygen, but not giving me quite enough. I even remember one of the nurses laughing and thinking that they were mocking me' **(Participant 12 Lines 85-87)**

Other participants described times when they felt they were witnessing the persecution of others:

'I do remember that two porters came to take away a man and I knew that they were going to take him away to kill him. And I got really upset because neither my husband nor anyone would believe me. I thought they were very cowardly and the thought of letting a man go to his death and not being able to do anything about it was awful' **(Participant 16 Lines 70-74)**

Some were very elaborate conspiracies and as you can see from participant 9's account they are wrestling between what they believed and experienced with their rational thought:

'They bought a girl in and she was one of these ones that had had bone grafts, one of these alternative, punk type people. Do you know the sort I mean? Anyway she had got a daughter who she was feeding on blood and milk...and the child had been trained like a dog so she didn't walk properly. She'd arranged for a boat load of this blood to come in so they arranged to get the delivery to where she was and then they would arrest these people. And I remember thinking that they just wouldn't do that not in a hospital but they did get the people. I remember hearing a gunshot a really load bang, this felt soooo real, but at the same time I couldn't believe that they would do that in a hospital it would be too dangerous. But then when I thought about it I thought well maybe it could happen ...' **(Participant 9 Lines 162-181)**

Several participants described feelings that they were at war or within a war zone:

'My mind connected Winston Churchill. And I was convinced...once again my mind was playing tricks on me. I already knew that the hospital had originally been built by the Americans during the Second World War and it is like a series of nissen huts. And although in effect, the bit I was in was a new building, I got the mental picture that it was an old nissen hut... For some reason I

thought we were still at war, that we were under fire with bomb shells going off. I distinctly remember ...' **(Participant 3 Lines 167-180)**

'I don't know where I was but I just remember being in absolute fear of my life. I thought it was a war going on. I mean I could hear all the kafuffle around me, gunshots, shouting, scraping, people milling around.' **(Participant 10 Lines 56-59)**

Another participant believed there to be a global pandemic which was supported by the presence of the surrounding technology:

'At this point I was convinced that there was a global pandemic and South Africa was the best place to go and get treatment as Europe and America were in a terrible mess... The one reason that I was convinced that it was a global pandemic was that I could see all of the screens opposite me in the beds and I was convinced that it was CNN telling everybody about how awful this pandemic was and how millions of people were dying in various countries and stock markets were crashing and you know and it was going to be a big recession and stuff like that.'
(Participant 12 Lines 113-115)

Watching Myself in an Unreal World describes the metaphysical aspects of My Useless Body. Participants appeared to feel physically, emotionally and socially disconnected due in part to their critical illness, their useless body and the technologies subsequently applied. Arguably the feeling of disconnection may be a function of time where participants perhaps felt more connected at the time of their experiences but have subsequently distanced themselves from their experiences upon their survival and recovery. Underpinning the reported experiences of

Watching Myself in an Unreal World is what appears to be overwhelming fear and anxiety. The presence of technology often exacerbates this fear and at times contributes to participants' delusions and hallucinations. Participants seemed to wrestle with what was real and unreal. The next section describes how participants made sense of these experiences.

Making Sense of It

The temporal nature of the participants' experiences is demonstrated with consideration of the following theme. Within the participants' accounts of My Useless Body there is a definite sense of THEN which describes what happened during the participant's time in ICU. In contrast to this there is the participants subsequent telling of and making sense of their story which in essence represents the NOW. The NOW includes the rational construction of the participants' story and seeking explanation of their experiences in the theme Making Sense of It. The process of constructing their story is not linear: participants do not present or seemingly understand their experiences as a sequential series of events. For some participants, however, an accurate timeline is important but not necessarily within the telling or understanding of the events. The theme 'Making Sense of It' comprises of 'Why am I Here', 'Searching for Familiarity' and 'Sorting the Real from the Unreal'.

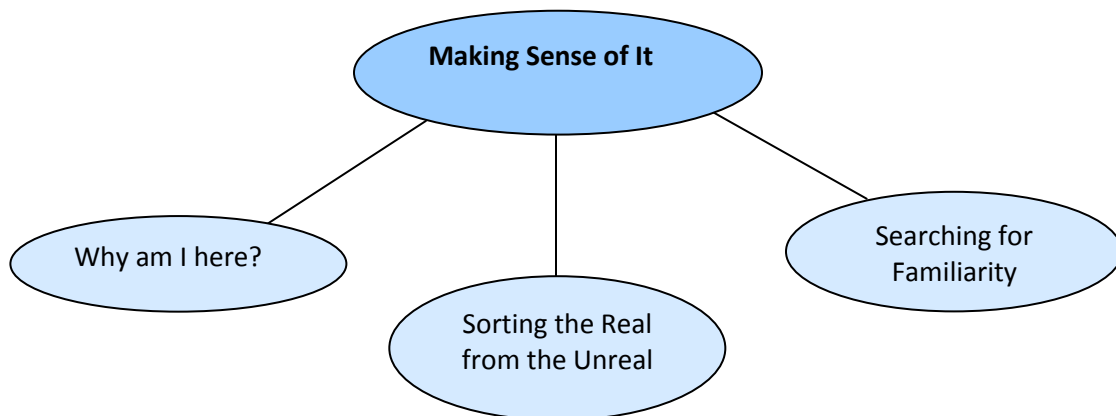


Figure 3: Schema of Making Sense of It

Why am I here?

The process of constructing their story involves the participants providing a back story or the context of their subsequent admission into ICU. Participants invariably start their story by describing the events immediately before their illness. Participants all described clear memories of the time leading up to their critical illness. They then describe a clear cut off point where, for what many of them described as rational thoughts or memories, stopped.

'...So we came to the [hospital] on Tuesday and had all the tests. I got diagnosed with pneumonia and was on the, the medical assessment unit ward overnight and on Wednesday they started me on the antibiotics... transferred me onto the chest unit..., put on morphine...and a mask....Umm and then that night, my wife stayed with me to eleven thirty....I felt a bit better and had a bit to eat. And then the memory goes. All I remember from this point is being pushed on a trolley to ICU. I then don't remember anything' (Participant 12 Lines 22-26)

'Well I was home and I had cooked Christmas dinner for everybody, all the elderly relations and what not. I was really struggling so I spent the afternoon, I think in bed. I don't remember much more of Christmas day. I don't even remember what I bought people for Christmas because I was just so ill. And then the night of the 26th December the last thing I can remember is coming down stairs and sitting with my husband' (Participant 8 Lines 16-25)

It is notable that at this stage of the story telling, participants generally emphasise the chronology of events and spend time making sure that the chronology is correct:

'Well I was admitted on the Thursday, the Thursday before Easter. No wait a minute it was the Wednesday. That is right because I remember going to the meeting at work on the Wednesday. Anyway, it wasn't until the next day when I really started to get bad. I didn't go to ICU until the early hours of Friday. So that was Good Friday. Yes that is right, it was Good Friday.' **(Participant 18 Lines 14-21)**

Participants all describe having patchy memories and often express frustration at not having the complete picture.

'My main feeling throughout it all was probably confusion. I didn't know why I was there. I didn't remember the accident. And it was only when I got to [Community Hospital] that [Husband] realised that I didn't know either! So he was going on about my car. And I was like, well what's wrong with my car. I don't want to be rude here but what are you going on about. He said, well don't you remember? And I said no... Because I didn't realise at that point that I had been in hospital for nearly a month' **(Participant 4 Lines 80-86)**

'Well I suppose they thought that over the period of time, somebody would have told me things. I think part of it was that they didn't realise that I didn't know.' **(Participant 3 Lines 67-69)**

In order to make sense of these incomplete memories, participants described the importance of having somebody, be it a health care professional or friend or relative, fill in the gaps.

'So I don't remember all the details, just snippets. My wife has told me some things. She told me when I was being transferred to the coronary care department' **(Participant 2 Lines 45-46)**

'[Wife] filled me in on all the odds and ends. So [Wife] has helped a lot, she has been able to clarify the details.' (Participant 2 Lines 336-341)

Conversely participant 9 and 16 suggested that they felt grateful for not knowing all of the details:

'[Wife] wrote the whole thing down and my son had taken some pictures of me in ICU so there are not like... So it is not, well I've got the diary and pictures if I want it. It is not something I feel that I need to sort out, do you know what I mean. So I haven't looked at any of it. Not a big thing really. I sometimes think that I'm better off not knowing [laughter]' (Participant 9 Lines 260-264)

'Well I guess it might make it easier if I did remember but actually I'm glad I don't remember the tube going down my throat and things like that because I remember being so sick that they had to put a line up my nose and I found that very distressing. So I am very grateful that I can't remember it.' (Participant 19 Lines 412-414)

The complete, chronological account of events leading up to their ICU admission appears to be important to participants. Together with an understanding of their physical ailments, the chronological account appears to form a framework upon which the participants' subsequent understanding of their experiences and the technologies they encountered is based.

Sorting the real from the unreal

Just as participants can describe a definite time when clear memories disappear, most participants can distinguish a time when they are suddenly aware that they are fully conscious and subsequent memories are vivid and clear- the point at which the THEN becomes the NOW. In between these two time frames, participants describe memories of sorts: many of these memories are hazy, some of these memories are based in reality, and others are based on their dream-like state or their distorted perception of events at the time.

It is clear from the participant's dialogue that during their recovery many participants spend a lot of time trying to distinguish what was real and was part of their dream world- in other words sorting the real from the unreal. Many participants described feeling as though reality and unreality are intermingled and sometimes inseparable. As such, participants often express difficulty in separating what they perceive to be a dream and what were real events:

'Because even now I have memories but I don't know whether they are real or not. And some of them are so bizarre I don't bother mentioning them to [Husband]. But you never know as ICU is a bizarre place. Anything is possible. So it is difficult finding out the reality and the dream world. You know trying to distinguish the two was the hardest thing for me.' **(Participant 4 Lines 434-437)**

'...My mum said do you mind if I go and get [stepfather], and umm and that conversation to me, and this is going to sound very strange, I thought this happened in a tropical clinic somewhere in South America. But that was a real event that happened in [City in the UK] and I've since found out that Mum did come in and she remembers having this conversation. It is like having a small

wedge or reality that gets put into your dream. This is why I have difficulty in deciphering what is real and what is imagined. Some things are obviously implausible, like the tropical clinic but other things, I can't always tell.' **(Participant 12 Lines 64-69)**

'The really strange thing about it was that it was obviously a dream because it was something my brain was making up because it was disjointed, you know? It was missing a lot of the basics as it were umm and it was you obviously totally implausible... Nevertheless it was sooo real that when I came round and I don't know if this was the effect of the drugs or maybe due to how ill I had been, but I found it, I could not separate the dream from real events.' **(Participant 11 Lines 278-283)**

Whilst sorting the real from the unreal, it is evident from the data that there is a distinct point at which the participant starts to make sense of their story. Many participants describe suddenly being situated in the present, in what they often described as being reality. Some participants describe a specific event or occurrence that triggers this turning point- participant 3 distinctly remembers a discussion with a member of the medical staff, whereas participant 1 describes their trigger as seeing the name of the hospital written on the towel or sheet:

'Well yes I remember I didn't know what was going on really but then I distinctly remember the Doctor eventually came round and said, 'Well you've been very ill and we have had to do a lot to bring you round' and I said ' Well, yes, thank you very much for giving me that information'. And it was then that it all began to make sense' **(Participant 3 Lines 332-338)**

'The only thing...it was several days, I felt we had been in an accident. Well I thought we were up [City 100 miles north of actual location] way, somewhere up there. Well one day, I, whether it was a towel or a sheet, but I saw [actual hospital name] written on it. And I suddenly realise where I was and I thought, Oh that's good I am nearer home than I thought! And then it fell into place what had happened. I'd overheard them talking and I also vaguely heard pneumonia one day when they were talking and I thought, Oh good it wasn't an accident and if that's pneumonia I should get over it, you know?' **(Participant 1 Lines 150-157)**

It is apparent that when they start to make sense of their experiences participants also come to realise the severity of their illness:

'Friends visiting told me just how bad it was and it wasn't until I only just found out that there were people from the Church there praying all night with me. I don't remember them being there but apparently they were. They did a shift system apparently- literally had a rota going. But I didn't know about that. I hadn't realised at the time how serious it had been until after.'

(Participant 5 Lines 392-396)

'Probably on the Friday, which was the first time that I can fully remember stuff...So it was a week after the accident. It was quite scary as you get so used to looking up and seeing a nurse there, all the time. You realise how dependent you are on them. It is like relying on them completely...I guess that is what made me realise how ill I was.' **(Participant 10 Lines 402-407)**

Searching for familiarity

Whilst trying to make sense of their experiences and sorting the real from the unreal, many participants described how they searched for factors that could orientate them. Such factors primarily included a sense of time and routine, familiar objects and people.

Participants described how they had no sense of time during their stay in ICU. Participants described that knowing the time was important as it gave them a sense of normality within what is otherwise a very confusing environment:

'I found the clock comforting. Time just ticking by as normal...' (Participant 2 Lines 56)

'Well before they moved my bed I couldn't see a clock or a window. But when they moved me, it was better because although there was no window at least I could make out the time. At least I could get a sense of time ...' (Participant 11 Lines 211-214)

Many participants described how they could not distinguish between night and day:

'Because when you are in that place there isn't a night and day. It all mulches into one. It is all one experience.' (Participant 4 Lines 393-394)

'Yes interesting. I think like the ICU especially the one in the [hospital]. It was like it was night time all the time. The lighting wasn't very good and I couldn't see the clock and I didn't know what time it was. Days went into nights. There was no concept of day or night or timings and because I wouldn't be eating anyway, it wasn't like they could say, Oh here is breakfast which

you could set a time by breakfast lunch and dinner. There was no orientation to time. There was no routine to framework your day.' **(Participant 5 Lines 312-318)**

As suggested by participant 5 above, participants did try to orientate themselves to time by assessing the routine or activities on the ICU. Participants described how these routines and activities assisted them in gaining a sense of time and chronology of their experiences.

'Towards the end I became more aware. I started to be more aware of the activity really, come morning everything kicked in there was lots of activity, people were up and about and then later it became more quiet the lights went down. The trouble was there were no windows. I don't think there were any windows. I don't remember any windows anyway.' **(Participant 8 Lines 145-147)**

'I still couldn't see outside so there was no natural light... well I had to decide whether it was morning or night. Quite often I could work it out by looking at what was going on and what the nurses were saying- what they were talking about.' **(Participant 17 Lines 215-218)**

Interestingly a lack of natural daylight was frequently described within the participant's accounts. Many described their memories of ICU as being dark, often oppressive with no windows, yet, as participant 5 describes, upon re-visiting the area found the opposite to be true.

'I didn't know whether it was night or day. I found that frustrating. At the time I thought I was in the basement of the hospital, so dark and oppressive. I thought that there were no windows or natural day light. There was no fresh air. However, I have been back to visit since and there are

windows [laughter]. And it is quite light and airy! [laughter] I don't know what made me think there wasn't.' **(Participant 5 Lines 317-323)**

The routine and necessary care interventions in ICU do not adhere to the traditional day/ night boundaries that might be expected in other clinical areas. Moreover the presence of technology and technological interventions in some instances served to disorientate the patient as frequently participants expressed frustration or confusion at interventions and activities occurring at what they perceived to be strange times of day/ night.

'I suppose they were doing stuff at strange times of the day. I remember them vacuuming, at least that what it sounded like, in the middle of the night! But thinking about it maybe it was day time- it was hard to say.' **(Participant 6 Line 94)**

'I must say I was puzzled as they took blood at all sorts of times and I looked at the clock once and it was one o' clock in the morning. I thought why do they want my blood at one o'clock in the morning?' **(Participant 1 Lines 144-146)**

Conversely some participants described the routine of technological interventions as helping them to orientate to time and found the routine comforting:

'Well, I quickly got used to it really. I knew that first thing the nurses would come and swap my breathing machine over. Once that happened I knew that shortly after I would sit out and then the physio would come and move me about a bit. And often the X-ray machine would come

around, that was so noisy- you could hear it coming a mile off. I quite liked watching the routine of it all. It helped pass the time' (Participant 14 Lines 256-261)

'They took such good care of me. I really felt looked after. I mean I couldn't sniff without them knowing. They were always taking my measurements and monitoring the screen...I mean every hour or so they were testing my blood...I found that reassuring that they were regularly doing that.' (Participant 18 Lines 397-412)

Many described a process of searching for familiarity. Most commonly participants describe how the presence of their family members featured in the construction of their story and making sense of their surroundings:

'Well, I'll tell you... just before I came round, I was going round and round and round in a dark tunnel and landed in white clouds, beautiful clouds. And then they changed to pink. And I was searching in them, madly trying to find [husband]. And I opened my eyes and there he was right by me. I was just desperate to find him' (Participant 1 Lines 81-85)

'For example I remember my wife being in my dream at one point and me feeling a bit better, and feeling a bit calm, thinking, 'OK that is [wife] and she is there that is good'. And then I also remember seeing my mother come in and asking well saying it is good to see that smile again and umm and that conversation to me well even though is wrapped up in this really weird and bizarre dream seeing them made me feel so much better.' (Participant 12 Lines 63-66)

One participant described how the presence of friends reminded them of life beyond their own unreal world:

'You just grasp to make sense of it all. And in my case, my wife died last year, I have no direct family. The fact that friends were allowed in, reassured me... It made it feel more normal like life goes on. Life isn't confined to the weird environment!' **(Participant 5 Lines 406-413)**

Often when participants encountered the unexplained they incorporated the experience or object into their dreamlike state and interpreted it as being something familiar and easily understandable. For example, Participant 5, when describing the noise of the ventilator alarm, describes how within her dream the alarm represented an unanswered door bell:

'No just that beeping because I didn't know what it was for ages even though it was right next to me so... It was weird but I thought that I was at a friend's house. I know this sounds very strange...Anyway, I felt that I was at a friend's house and I was laid on their settee and it was the door bell that was beeping. And I kept thinking there is someone at the door, there is someone at the door. Will somebody answer the door?' **(Participant 4 Lines 304-311)**

Participant 10 describes how the sensation of a femoral intra-aortic balloon pump catheter felt like a bunch of keys in his pocket.

'Oh yes, another one was that I remember trying to get the keys out of my pocket for the van. I thought I was in the van so I asked my wife if she could drive the van. She kept saying the van was ok and stuff. So I remember desperately trying to get the keys out of my pocket but they

kept pulling my hand away. In hindsight that was where my balloon pump was so I think the nurses were trying to prevent me damaging it but I can remember trying to get the van keys but not being able to.' **(Participant 9 Lines 184-189)**

As well as searching for familiarity, participants stressed the importance of 'normality'. The importance of normality was demonstrated by Participant 16 who described how photographs of her garden at home were of great comfort to her:

'I told them to take photographs of the garden. So my son took lots of photos of the garden and put them, bought them all up and put them in a big pin board at the end of my bed. I remember looking at them for hours when I started to get better and they were a great comfort for me.'

(Participant 16 Lines 43-46)

Other participants valued doing 'normal things':

'I do remember having a sensible conversation with the nurse who told me she was getting married in America, so I obviously had some glimpse of being more normal. So I do remember talking to her about her wedding. It was just really nice talking to her about something normal'

(Participant 16 Lines 59-63)

'And I tried to do things because it reassured me I was normal. I even booked my hairdresser to come into ICU and she washed my hair for me [laughter]. But I was desperate to do things that made me feel normal because that is so important.' **(Participant 7 Lines 215-221)**

'I clearly remember on Sunday night, because I think I was given a digital radio and I was listening to radio 4 and I finally, you know, this is awesome, because I can finally separate reality from not. I was doing something normal, whereas up until that point I hadn't been able to. Up until that point I was very confused.' (Participant 12 Lines 43-44)

The theme Making Sense of It describes how participants rationalise and understand their experiences in ICU. Participants seemed to value a chronologically coherent understanding of their experiences. They often relied on family to help them sort real and unreal memories and fill in the gaps of their memories. Participants valued familiarity during their stay in ICU as a means of comfort and making sense of their experiences.

Technology and Care

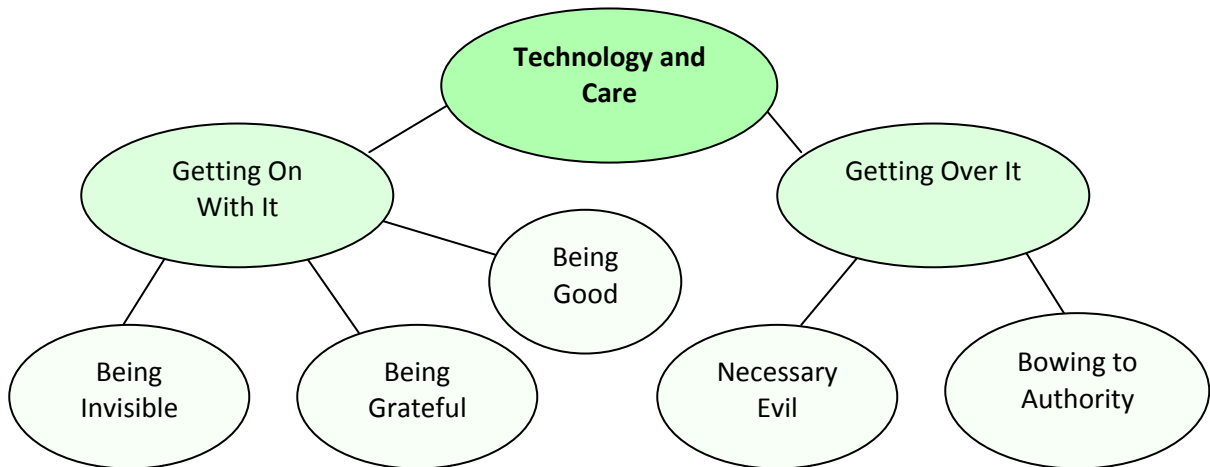


Figure 4: Schema of Technology and Care

Technology and care seeks to address the key research objectives which were to explore the patients' perceptions of receiving care in a technological environment and how technology has

influenced their experience of care. The preceding themes (My Useless Body and Making Sense of It) provide the contextual framework to participants' accounts. This theme also gives insight into patients' personal coping strategies, the social and organisational structure that prevails in the intensive care environment and the role of the health care professional.

Technology and care were not viewed by the participants as being mutually exclusive. The presence and application of technology was almost taken for granted and recognised as being imperative to both their care and recovery. Most participants described how they felt that by attending to the technology nurses were caring for them and thought of it as one and the same:

'Because they were just, you know, going out of their way to be so kind and caring. All of that team were just fantastic. My own allocated nurses, so it was one to one and they just watched everything, always watching for this and that. Nothing escaped their notice. A minute an alarm went they saw to it, the minute the numbers on the screen changed they checked it. They were constantly monitoring and things. Yes I felt very well looked after.' **(Participant 8 Lines 165-172)**

Even after probing many participants could not separate management of technology from the care they received:

'It is interesting because in some of the research literature there is a suggestion that nurses who work in high technological environments like ICU seem to be more concerned with the technology. Whereas what you have just described...' **Me**

'I wouldn't say that. I would say, no the exact opposite. They care as equally for the patients as they do for the machinery and what is happening with the patient and the actual care the

patient gets...because you know some things, unpleasant things is what is required, but it is all to look after you' (Participant 17 Lines 437-446)

'A lot of the literature suggests that sometimes nurse's focus is on the machine and not the patient, did you feel that at all?' Me

'Never, never! Not at all. No the focus was on me.' (Participant 13 Lines 372-378)

Further to this, participants appeared to view health care professionals as an extension of the technology- as the manager, controller and executor of technology, nurses become the technology. Participants frequently referred to a variety of technologies within their accounts of their experiences but frequently didn't refer to the health care practitioner applying, managing and monitoring them. For example, many participants refer to being 'suctioned'. Participants articulate their experiences of undergoing endotracheal suctioning at great length but do not distinguish between the technology used to perform this task and the person applying the technology. In other words the nurse appears to be encapsulated within the whole process.

'Suctioning was the worst thing....I hated it. When I could feel phlegm in my chest I knew the tube would be coming... I dreaded the cap coming off the thing, then I knew cough, cough, cough for the next few minutes. It was so exhausting' (Participant 19 Lines 46-47)

Participants were however able to articulate elements of nursing care where the nurse was seen as a nurse, separate to technology. However, interestingly when describing nursing care, participants appeared to equate 'care' with maintaining personal hygiene such as cleaning teeth, hair and face or making tea and fetching drinks.

'No they were great in ICU, doing the little things that meant a lot to me that wouldn't necessarily you know, because normally you would do it yourself normally you just comb your hair or wash your hair and wouldn't think twice about it. But you know when your hair is dirty and somebody washes it for you, you just feel well its heavenly, you feel fresher and well nicer. It humanises it. I guess it adds the human touch!' **(Participant 8 Lines 105-109)**

'Even like things like washing my hair for me cleaning my teeth for me. You know making sure that the personal things were looked after as well, not just the medical things. So my wellbeing was important to them. You know washing my face in the morning... It makes such a difference, you just feel more human I suppose. No and that is what I really appreciated.' **(Participant 13 Lines 78-82)**

The majority of participants only described the practical elements of care- very few described psychological or emotional aspects of care. When asked, participants did describe how the nurses supported their emotional or psychological well being:

'You seem to have described some of the practical care, as in the things they do for you, but what about the emotional care, you know...' **Me**

'If you need to sit and talk then they will sit and listen. Umm they would ask, they would always ask you how you were feeling, had you got any problems, was there anything you would like to talk about. And you know they would try and fill you in on the day, what was in the news, things to try and keep you upbeat. And normal things, normal everyday goings on.' **(Participant 15 Lines 107-114)**

'I mean talking to [nurse in ICU] he said 'I am here to look after you, I'm paid to look after you, so anything you want, you ask and actually he made it a lot easier because he was really jolly, he had a brilliant sense of humour, he'd tell jokes and make me laugh... We built up a really good rapport between us and that made it a lot easier...it was like sitting with a friend. It made such a huge difference. I think it is breaking that barrier.' (Participant 7 Lines 272-280)

Overall within the theme of Technology and Care it is clear that participants do not distinguish technology from care to the extent that the nurse themselves are often seen as an extension of technology. Where participants do describe nursing care, they tend to focus on the non-technological interventions such as personal hygiene, comfort and providing drinks. It is not clear if participants do not recognise that caring for technology as part of nursing care or if technology and care are so intertwined that the carer becomes the technology.

There are two key sub-themes that further characterise technology and care. Participants described in detail how and why they cope with and endure the applied technology. These themes are 'Getting On With It' (how they endure technology) and 'Getting Over It' (why then endure technology).

Getting On with It

Participants describe in detail *how* they endured the technologies that were applied during their stay in ICU. This theme is predominantly concerned with the THEN, in other words participants' recalled perceptions at the time of their critical illness.

Participants appeared to accept some of the invasive technologies, in particular ventilatory support with a certain amount of stoicism:

'How did you feel about being reliant on the oxygen and BiPAP?' **(Me)**

'Well it was just one of those things wasn't it... Well I didn't like it on but, well you are ill so you just have to put up with it. In the scheme of things it didn't seem so terrible.' **(Participant 14 Lines 222-226)**

'Did you find not being to talk frustrating?' **(Me)**

'No not really, that was just how it was. It was like the ventilator and stuff, it didn't really trouble me I just knew that I was on it. So I couldn't tell you it was awful because I don't remember that bit. I just knew I was on it and I had to be so that was that.' **(Participant 9 Lines 94-97)**

Many participants when probed as to how they coped with often invasive and uncomfortable technologies described how they seemingly accepted their situation describing it as 'just one of those things' **(Participant 17 Line 51)** and felt they had to look forward and 'just get on with it' **(Participant 17 Line 52):**

'Umm and um you know that is it you just have to put up with it, Really. It is no good moaning if you want to pull through the other end you have to just go for it. Keep going.' **(Participant 5 Lines 367-369)**

'Well obviously you know I am grateful and it is very fortunate that I came through it and it makes you more appreciative of life perhaps but I don't dwell on it. It is not like it is something

that is frightening so I just look forward. I've never been someone who looks back. So I knew I was there, I knew I was ill but you know, that was that.' **(Participant 13 Lines 354-357)**

As already indicated all of the participants were white, English and arguably a 'stiff upper lip' is a stereotypical character trait, therefore the stoic acceptance of technology and enforced environment and routines may be particular to the cultural heritage of this particular research cohort.

Participants often tried to make light of their circumstances by adopting a humorous outlook.

'Yes they actually removed the trachy just a couple of days before I left ICU. It was only a couple of days. I remember [son] came to see me and I could just say 'ha ha ha' I was just getting a little bit of sound. Oh it was quite a relief to be able to make a noise. The little grandchildren came in and said- you sound like a darlek granny! [Laughter]' **(Participant 1 Lines 222-231)**

'I didn't like the curtains around me, I liked the open space. It just felt so cramped. Like being in a box. Surrounded by stuff, and people, so many people. Some days it was like market day at [Busy Market town in the UK] [Laughter]' **(Participant 4 Lines 165-168)**

The above quotations demonstrate how the participants were able to retrospectively make light of their situation (the NOW), however, there is some evidence to suggest that some participants adopted a humorous outlook as a means of coping at the time (the THEN) even when confronted with something that they acknowledge to be upsetting, painful and as participant 7 suggests degrading:

'I mean when you are reliant, having to have somebody shower you and go to the toilet with you and clean your teeth it is degrading and to be honest with you I think that is what gets a lot of people down. I just made fun of the fact. I used to laugh at myself at not being able to do stuff. And that would make me more determined to get better. I used to view it as a challenge.'

(Participant 7 Lines 223-228)

'They kept trying to take blood and they would puncture me up here, and touch up there, and punch me down here, and punch me over there, and I said, 'Well I'm empty! You've taken it all!' And do you know I said to them, 'I feel like a sieve! [Laughter]' **(Participant 2 Lines 196-199)**

Participants endured technology and 'got on with it' and approached this with both stoicism and humour. This theme is further characterised by consideration of participants reported feelings of 'Being Invisible', 'Being Grateful', and 'Being Good'.

Being Invisible

Within the participants' accounts, technology was often in the spotlight with the participants describing themselves as being in the shadows. Participants often portrayed themselves as being invisible relative to the technologies that they required. This sentiment was reflected in participant reports of impersonal care where health care professionals were more interested in the technologies surrounding them:

'I felt cared for but it did seem impersonal at times, more matter of fact all round the, in kind of the, well they did examine me but I felt they were more interested in what the machines were telling them. I mean they probably were, because let's face it the machines could probably tell

them a lot more than I could tell them. I felt just separated from it, I didn't know what was going on and the person that they were discussing the person attached to the machines wasn't me, like it was somebody else.' **(Participant 6 Lines 156-161)**

'I remember the nurses looking at the computer on the right hand side. I remember them typing into that all of the time. Umm when the doctors came around it was almost as if they were only interested in the screen, they weren't interested in me as a person. It was more... it seemed impersonal somehow. You know they were only interested in the computer and what was on the screen.' **(Participant 5 Lines 98-102)**

Participants described how care givers as well as focussing on the technology also appeared occupied with various measurements test results and organ function. As a result participants frequently described themselves in terms of the status of their organs, their diagnosis or physiological measurements. Participants seem to view themselves as objects of observation and physiological manipulation.

'That was when my lungs were bad...with the pneumonia, you know? I had the trachy in by then...So they were trying to get the oxygen up as it was really low.' **(Participant 17 Line 35-36)**

Patients often described how they felt lonely and invisible in the presence of technology:

'Even though they were no further away than the corner of the room. I still felt very alone. I couldn't make myself heard. I'd got no strength so I couldn't bang anything. I looked around and

thought is this it? Just me? I've never been surrounded by so many people and felt so alone. I've never had so much attention yet felt so neglected.' **(Participant 4 Lines 192-197)**

Participants described invisible care, whereby they described caring interventions and activities but did not see them occur. Frequently the nurse's activities were a mystery to the participant—they knew they were doing something but it was unclear what. Caring activities were going on around them but not necessarily to them or with them. The orientation of the nurse's desk situated behind the patients' beds resulted in participants not being able to clearly view activities. Arguably this limited view contributed to confusion and feelings of loneliness and paranoia:

'I know that I was getting a bit frustrated with the fact that it seemed as most of the nurses kept disappearing behind me as the machinery was behind my head and they seemed to be doing things there. I felt as though I was on my own and I would speak, and they would say, 'Oh I'm here' but I would wonder what was going on behind. It made me paranoid, not knowing.'

(Participant 3 Lines 451-455)

'Because most of the time the nurses were behind so I was unaware. So all I remember is hearing voices but never ever seeing the nurses or seeing their faces so umm. I don't ever remember having nurses come to the bedside but I guess they must have done. They must have done...'

(Participant 9 Lines 243-246)

Participant 15, when asked, has no memory of any health care professionals approaching them during their entire stay within ICU. They clearly remembered care activities happening but do

not remember who, if anybody carried them out. Participant 8 when recalling the nurses involved in their care described them as being *'kind of faceless...'* This lack of memory of any human contact demonstrates the feelings of impersonal care. Another participant didn't describe the nurses as being complete humans but described them as *'floating heads'*:

'I used to just doze on and off day and night really and umm and then I would just open my eyes and see little floating heads...' **(Participant 1 Lines 250-251)**

The participants' perception of *'faceless'* care further exemplifies the notion that health care practitioner become an extension of technology. Within the participant accounts it appears that the nurse is so eclipsed by the enormity of technology that they too become invisible.

Being Good

Participants' accounts revealed an unspoken set of rules, and expected standards with which participants complied. Participants' compliance represents an almost routed acceptance of the technologies imposed upon them. The participants' unquestioning acceptance was demonstrated in the participants' adaptation to the ICU environment and the resultant routine. Participants accounts demonstrated that that the routine of care and even clinical decisions made were ordained by the presence and application of technology and technological interventions:

'I wanted to walk, but of course I couldn't. Mainly because of all the drips and things. I was allowed to stand up with the physio lady but that was that.' **(Participant 10, Line 43-46)**

'Oh that was the annoying thing. The speech and language people didn't get to me for a few days. So of course I was dying to eat, I couldn't drink, nothing. They used to give us these little sponges to suck. They were horrible. But they would stand over me and make sure that I didn't swallow...I was a bit frustrated as I had to wait for the language people to say yes it is OK...'

(Participant 4 Lines 453-461)

Participants appeared to learn the routines and complied with the expectations of the system as they expressed an overwhelming fear of being a burden both to health care professionals and their families. Participants described how they tried not to disturb the nurses unnecessarily- often so as not to disturb the perceived enforced routine that is set by the presence of the technology.

'I just felt that I was putting on them [nurses] all the time. I couldn't do a thing myself so I just felt such a burden.' **(Participant 15 Line 79)**

'I tried to keep still so I wouldn't disturb the lines. They kept alarming, I will never forget the sound of that alarm!.. Anyway, every time it went off somebody would come and re-set it and every time I moved it would go off again. I hated that they had to do it.' **(Participant 19 Lines 103-104)**

Participant 8 described how they did not want to be a burden to their family members:

'I had put my parents through a lot of stress and my mum's got cancer and that I was putting her though extra stress that she didn't need. I didn't want to be a burden on them' **(Participant 8 Lines 14-16)**

Participants expressed guilt at having to disturb health care professionals even when it was beyond their control:

'You see I was a little bit stressed about this beeping. But not only that, the nurses would come over, check it [arterial line], check there was no blockage or whatever, and I felt as though it was my fault that it was beeping and I was disturbing them. Do you know what I mean?... I felt they were getting up, you know for me...Somehow, I felt guilty that I was causing trouble...' **(Participant 4 Lines 212-215)**

Some participants described how they felt they weren't deserving of the care that they received, frequently suggesting that other patients were somehow more deserving:

'I felt guilty at making them do everything. Because my arms were tied up I couldn't even blow my own nose. I had to keep calling them. I know it sounds stupid as they are there to help you but you do feel that you are putting on them as they could be doing something for somebody else. In my head I felt OK and I kept forgetting that physically I wasn't capable.' **(Participant 7 Lines 45-47)**

In particular participants didn't like asking nurses to help with more unpleasant tasks such as toileting:

'Well I remember getting terrible diarrhoea. That was just the worse thing. It was awful just because you were putting on the nurses there was a lot of extra work and I not being fully convinced that they didn't mind dealing with it. They always said that they didn't mind but I wasn't totally convinced. Do you know what I mean? Just because everything else you can put up with but that... I just wasn't convinced that the nurses didn't mind dealing with it. So sometimes I just felt like I was a burden, I felt guilty about asking them to do it.' **(Participant 9 Lines 236-240)**

Participant 7 suggested that they relied upon technology so that didn't have to disturb the nurses as much:

'No that morphine pump was my saviour. It was good because it meant I didn't have to bother the nurses. I mean I just felt guilty more than anything when I had to ask the nurses to do stuff, because I am very independent person. I hate being run around after.... Yes I hated it, asking for help. I just felt that it shouldn't be necessary, I should be able to do this myself. I just didn't want to get the nurses to do anything like that.' **(Participant 7 Lines 305-310)**

Many participants described how they felt guilty about being ill in the first place. Some also blamed themselves:

'Yes I think I felt as though I didn't deserve to be there, that I shouldn't be there. And it was all part of this guilt thing. That I had bought it on myself that had I acted earlier maybe I wouldn't have got into this state.' **(Participant 11 Lines 89-91)**

Conversely some participants felt that their recovery was dependent on a partnership between themselves and the carers. Participant 6 describes this as teamwork:

'I knew myself that the only way I was going to get any recovery is that I had to exercise. I've always been of the opinion that treatment in hospital is team work. It is not just the nursing team and the medical team it has also got to include the patient. The patient has got to be part of the team otherwise you are wasting your time. So I tried to be a team player and if they said walk , I'll walk. If they said do this or that, breathing exercise, I did it. If they said I needed this drip, that drain, I accepted it.' **(Participant 6 Lines 293-300)**

Participants appeared to comply with the applied technology in order gain acceptance amongst their carers. Participants often strived to please their carers:

'So when I had it [tracheostomy] and they changed the tube [to a Passy-Muir speaking valve] it was really hard to breathe but it meant that I could talk. I was so, so tired it was such an effort. But I put up with it and tried my best. The nurses seemed really pleased when I managed to keep it on so I did try my best.' **(Participant 13 Lines 356-359)**

'So I remember for example trying not to cough and lying perfectly still because I knew that I would result in sucking [tracheal suctioning] and I also knew that it would result in setting off the alarm which disturbed them, you know, how ridiculous!' **(Participant 12 Lines 179-181)**

Being Grateful

Participants unanimously had very positive perceptions of the health care practitioners involved in their care. When asked to describe the care that they received participants almost automatically described it as wonderful, fantastic and other similar adjectives:

'Because they were just, you know, going out of their way to be so kind and caring. All of that team were just fantastic.' **(Participant 8 Line 230)**

Many praised the nurses for working hard:

'Yes I have been very well cared for. Because I mean it was wonderful on there- on ICU and the other place, coronary care. Every time my wife came in she always commented that the nurses were doing something. Moving me around all the time. They never stopped. Wonderful. They did work hard. Nonstop. Yes...' **(Participant 2 Line 106-109)**

Do you remember what the nurses were doing? Me

'Well you know, all sorts. They were always doing something. Of course it is all computerised now so they were tapping away on the screens. I don't know what they were doing half the time [laughter]. You know sometimes I was glad when they sat down as it was exhausting just watching them! All through the night as well, they were there. Never left me alone.' **(Participant 3 Lines 65-72)**

Many participants expressed their gratitude towards the care within the context of their physical recovery with many commenting that without this care they would not have survived:

'But I must say they were extremely good. Very gentle and very thorough, so I didn't have any bed sores at all.' **(Participant 1 Line 23)**

'Well obviously I am very pleased about how it has turned out and ummm as I said to the Doctor who came round that day, 'I have got absolutely no complaints about the treatment' and I said 'it is absolutely superb' I said, because I realised that I had been pretty bad and I said, no complaints what so ever ...' **(Participant 2 Lines 245-249)**

According to the participants accounts some viewed technology with awe and thought it a quality indicator- the presence of sophisticated technologies was often equated with good quality care:

'But I mean the nurses had got their computerised thing here and I had only just got to lift a hand and they would be by me. I thought the treatment and care was absolutely superb.' **(Participant 1 Lines 399-404)**

'The machines and what-not they had were unbelievable. That one for my kidneys! It was like something out of a sci-fi movie! I honestly couldn't have asked for better care' **(Participant 14 Lines 278-279)**

Praises were largely unprompted and appeared genuine, however, participants frequently demonstrated a clear tension as there were occasional inconsistencies in the participant accounts. Some participants extolled the excellence of the nursing care in one sentence but then

went on to describe negative aspects of their care later in the interview. Negative comments were often accompanied by an apologetic *'I shouldn't say this as they were only doing their job...'* (**Participant 2 Line 105**) as if making excuses for their perceived deficiencies in care. For example, Participant 4 describes the nursing staff as *'brilliant...they were just fantastic'* (**Line 398-399**) yet when describing a specific element of care (administration of night time sedation) the participant was critical of the care received:

'I used to get quite anxious come the night shift because I couldn't sleep. And I used to... and this used to make me worse, they would give me these sleeping drugs and I didn't really want them. So it wasn't a nice experience...because when you are in that place there isn't a night and day... So I don't think they should try and force you to sleep when you can't...We can't all go to sleep like good little boys and girls and they just didn't understand that.' (**Participant 4 Lines 384-395**)

The tension between adulation and censure perhaps correspond with the temporal element of their experiences of technology within ICU. In the NOW, after a period of reflection on their survival from a critical illness, participants are grateful and therefore perhaps describe the care as marvellous, however in the THEN, experiences were described as being far from marvellous. It would appear that with the benefit of hindsight, participants have rationalised the presence of technology as being necessary and life-saving but at the time, these technologies resulted in loneliness, isolation, discomfort, and a perceived impersonal and dehumanised care.

Getting Over It

Getting Over It provides a rendering of *why* participants endured the technologies applied. Acceptance and/or endurance of technologies in ICU relate to the social and organisational

culture of ICU and participants consideration of long term outcomes. These are explained in the two subthemes 'Bowling to Authority' and 'Necessary Evil'. Both sub-themes depict a disruption to participants' agency and also demonstrate a temporal variance in perceptions and experiences. - the THEN and the NOW

Bowing to Authority

One important aspect of tolerating technology was the fact that participants felt they had no choice and were for the most part bowing to both the authority and judgement of the health care professionals. Within the participants' accounts there is a sense of enforced compliance with and to some extent dependency on technology. Participants appeared to surrender their agency to technology and put their lives in to the hands of the health care professionals. Many participants recalled 'giving in to it' and 'letting them get on with it' which demonstrates a lack of control and capacity to influence their care. On one hand, participants recognised the expertise and clinical judgement of the health care professional:

'It's hard to say, because obviously they are the experts and you have to bow to their better judgement... Regardless, it is their job they know, they are mending you. So it is not going to be comfortable, easy and nice by the nature of it.' **(Participant 4 Lines 58-64)**

'I trusted them- they clearly knew what they were doing so I just left them to it' **(Participant 17 Line 94)**

Within some of the participant's accounts, it is clear that they not only trust the health care professionals who apply the technologies but also have an unreserved trust of the technologies

themselves despite not necessarily understanding its function. There is a sense within the data that participants often trusted technology because the health care professionals do. Participants appeared to take the effectiveness of the applied technologies for granted:

'Well, I understand that ultimately it [ventilator] was there to make me feel better. So there was no point worrying about it. I had to trust that it would be OK and do its job.' **(Participant 15 Lines 321-323)**

On the other hand compliance with technology did not seem to be about trust as participants also described having no choice and viewing the staff as being in a position of authority or being *'at their mercy'*:

'Not knowing what was going on. You just, you are just so vulnerable. You have to put yourself completely in their hands. At their mercy. Hooked up to go knows what. I couldn't even lift a spoon to my lips' **(Participant 3 Lines 129-131)**

'I mean really, you just have to do as they tell you. At the end of the day they are in charge.' **(Participant 18 Line 45)**

'Was the tube helping you breathe?' **(Me)**

'I don't know what it was doing, I guess it must have been. Although I remember feeling quite suffocated...they often put a tube to make me cough and ...I tried to control it by holding my breath but I couldn't, it made it worse. Eventually I got used to it I suppose. I gave into it. Awful...' **(Participant 2 Lines 67-75)**

A lack of the ability to communicate was frequently identified as an explanation of participants' unquestioning compliance:

'So how did it feel not being able to talk?' (Me)

'Well, I just got used to it. I didn't understand why I couldn't talk. That was the thing... I just led there and almost gave up to it. It got to the stage where I didn't bother trying. I didn't know what had happened you see. Nobody told me, so I just gave in to it.' **(Participant 3 Lines 98-106)**

'I guess I left it to them. I couldn't do anything or say anything so I just left it to them really.' **(Participant 5 Lines 387-388)**

'It's amazing isn't it that you can have so many bits and bobs going into you and you don't think to question it at the time. Yet now, now if you asked to put one of those things in, well of course I would want to know. I would want to understand. I guess you are too out of it though so you just don't care.' **(Participant 18 Lines 342-346)**

The acquiescence of control therefore appeared to be not through choice but almost due to a state of non-being. Due to their critical illness participants did not view themselves as being active players in their care. Although participants acknowledge that surrendering their agency to health care practitioners and technology brings about certain benefits. As we have already seen within 'Being Good' theme, participants feel that complete compliance may bring about acceptance and approval from health care practitioners but it is also evident that surrendering to technology offers the participant some security and hope of recovery.

It is evident that some participants whilst outwardly bowing to authority and surrendering their agency made furtive attempts to reclaim some control. Participant 18 made attempts to influence their care by deliberately slumping in the chair in the hope that they would be returned to their bed where they were more comfortable. Participant 16 described how they bowed to authority and endured ICU and the associated technologies on the surface, but were mentally conspiring against what they perceived to be authority:

'I think the staff amazing, the staff were, well I felt safe and secure I think the only thing that keeps bugging me, and I don't know why this is, for saying I have very few memories of ICU per se, but I remember coming around and thinking I never ever will go through this again. I will never, ever, ever come back here. If it came to this again, I would go to Beachy Head [a notorious suicide spot in the UK] or if I could afford it Switzerland [where assisted suicide is permitted]. But I remember feeling very, very strongly that I will never suffer this again, I will never go through this again and yet I have no memories of suffering really. So I can only think that subconsciously there must be more memories there. And do you know I remember hanging on to these feelings even when I was getting better, because after ICU I stayed in hospital for another three weeks. And all of the time when I was getting better, that was my secret. That I would never ever go through it again. I pretended to the family that all was OK but I would never go through it again.'

(Participant 16 Lines 90-98)

The participants 'secret' enabled them to endure the experience of ICU and the associated technologies and also acted as a motivation for them to continue with their progress and recovery. Similarly, other participants also tried to reclaim control of their situation by

attempting to dissent against the perceived authority. In doing so it revealed that the participant valued having choice:

'I tried to discharge myself at one point... and that was purely and simply to see if I could. I felt that I was being kept prisoner. But that was just my thought process that was so screwed up. And I was signing all these forms to say Yeah Yeah whatever, just let me go. And the hospital director came to talk to me saying 'Well we don't want to do the mental health act but we'd rather you didn't leave.' Course that made me worse- paranoid by this stage. And all I could see was that they wanted to keep me there. But as soon as they said that I could go, I didn't want to. So I stayed not because they wanted me to but because I did.'

(Participant 4 Lines 100-107)

Bowing to authority again demonstrates that participants have a lack of agency and highlights how participants try to reclaim some control. This raises the question whether it is not technology itself that leads to depersonalised care but the lack of individual and personal involvement of the critically ill patient in their care.

Necessary evil

It is apparent on examination of the data that participants endured technologies by recognising the benefits of the applied technologies, frequently regarding them as a '*necessary evil*' **(Participant 19 Line 87)**. Within the participant data there are paradoxical descriptions of technology as being both distressing and unfamiliar as well as providing a sense of security and hope for recovery. Participants frequently rationalised that the benefits of complying with the treatment outweighed its discomfort.

Participant 1 described the relative benefits of intermittent pneumatic compression stockings:

'And they had these things that you put your heel into, little socklets and they fitted across and then periodically one would pinch and the other would contract you see. Well this was fine in the daytime but I wasn't so keen at having these movements going on at night ... But I must say they did keep my ankles really good. There was no swelling at all.' **(Participant 1 Lines 162-169)**

Participant 3 and 4 recognised the discomfort of tracheal suctioning however recognised that this invasive procedure actually bought them physical comfort:

'Umm and I vaguely remember bits and pieces. I remember not being able to breathe very well and them sticking a big long pipe down my throat. But I didn't know that that was what they were doing at the time. I just know that they were sucking something and it made me feel better' **(Participant 3 Lines 45-48)**

'Well it [tracheal suctioning] happens a lot of times too. They were doing it about every hour. That's the thing. And all through the night too. Because it feels like you... when you have a frog in your throat and you try to clear it, well I couldn't do that so it was a great relief. When I saw the nurse approaching, I thought, great she is going to suck all this rubbish out. So on one hand it was uncomfortable but on the other it was brilliant because it made me feel better.' **(Participant 4 Lines 158-166)**

Some participant described how due to the relief that the technology proffered they became dependent on the technology:

'I remember taking the ventilator out, I remember them taking like a vacuum pipe out. I distinctly remember it felt like they were sucking all of the air out of my lungs! But once that was gone, uhh yes I did have breathing problems after that though as I was on oxygen after that for a long time. It felt like my saviour... I remember feeling quite dependent on it and panicking without it.'

(Participant 5 Line 253-259)

As well as the potential of physical comfort, the presence of technology provided the participant with security and optimism for their recovery and survival. Participants felt secure in the presence of technology as they perceived it to be making up the short fall of their dysfunctional body. Technology stepped up where their body failed:

'It [non-invasive ventilation] was just to increase my oxygen levels because obviously I wasn't breathing quite right. At that point I had more liquid in my lungs again. Because they literally took a litre and half they said... I remember it forcing the air in and although it was a relief, quite a big relief as it was helping my breathing.' **(Participant 8 Lines 57-63)**

Technology also offered hope of recovery and survival to the participants. Participants seemed reassured that survival was a possibility as long as technology was there. It was the promise and hope of recovery that technologies represent enabled participants to tolerate them and move them beyond the periods of distress and physical discomfort.

'I new that even though it [nasogastric tube] was horrible it was doing me good...that it was helping me to build my strength and get better.' **(Participant 19 Line 89)**

Throughout their stay on ICU, participants gained knowledge of technologies and used technologies as a means of reassurance that they were on a pathway of recovery. In particular some participants staged their recovery by technology and very much perceived technology to be an integral part of their recovery process. Technology seems to represent the recovery trajectory where technologies are applied or removed at various stages of the illness and recovery.

'... So as each drip disappeared and they took off the things from my leg I knew it meant that I could do more for myself.' **(Participant 7 Lines 236-237)**

'When I first woke up, I thought ok so I have survived this one, I am awake and conscious. And then you start seeing how dependent you are on not just the people around you but like the machinery. I mean the oxygen, the drips and everything. And you are aware of your injuries so every little bit of independence you get back means so much. It means that you are getting back to normal.' **(Participant 8 Lines 365-369)**

Participants frequently organised their story around the presence or absence of various technologies. The removal of ventilation and tracheostomies seemed to be a meaningful milestone amongst many of the participants.

'I mean coming on and off it [the ventilator] was OK. Even though it was really hard work without it on, I knew that if I could put up with it a little longer each time I was getting better' **(Participant 10 Line 245-247)**

'Yes they actually removed the trachy just a couple of days before I left ICU. It was only a couple of days but I knew that I was on my way then...' **(Participant 18 Lines 56-57)**

As well as demonstrating progress, some participants used the presence of technology as an indicator of a deterioration of their condition:

'Yes I had it [NIV] on in intensive care. It is one of these... well it is quite tight and it forces air into your lungs... I mean they did take it off for a while after a few days but they are always monitoring the oxygen levels in your blood so I had to have it back on again and I remember thinking 'Oh no, this is a step backwards. This is not good.' **(Participant 6 Lines 84-87)**

'I remember my family saying that they were obsessed with all the machinery and when I was getting better I became obsessed with it. I became curious about what the nurses and Doctors were bothered about. I wanted to know what the machines were telling them. So when the alarm went, I was like, oh my God, what's happening, what has gone wrong?' **(Participant 16 Lines 178-182)**

In addition, some participants described how they felt that technology hindered their progress:

'Even when I was recovering, I felt as though I was waiting for things outside of my control. You can do this once the trachy has gone. You can't do that until the tests come back. Lah de dah...' **(Participant 4 Lines 447-449)**

'Before they changed them [drains] I couldn't move but then I just hung them on the walking frame and it was fine. Until I was walking around I felt quite hemmed in by them. I was glad when I could move with comparative freedom. I felt less restricted and finally getting back to normal.' (Participant 5 Lines 312-315)

The findings from this study demonstrate that technology and care may be simultaneously viewed as being mutually exclusive and as being so closely intertwined that one cannot exist without the other. Participants' accounts reveal that participants experiences of technology and care or care in a technological environment oscillates anywhere between these polar opposite view points. On occasions care and technology are so closely intertwined the two are described as one to the extent that participants do not even distinguish between technology and the carer. On other occasions participants do distinguish between the care they receive and technology and do view them as separate elements such as when describing their personal care.

Participants described how they endured technologies with stoicism and acceptance but at times felt invisible and subject to faceless and impersonal care. Conversely participants simultaneously expressed immense gratitude and adulation towards the nursing staff caring for them. Participants also described how they acquiesced to an unspoken technological routine not wishing to place a burden on their carers and family. Participants appeared to bow to authority and expertise of their carers which demonstrates a lack of agency experienced by some participants. Participants frequently viewed technology as a necessary evil which whilst uncomfortable, invasive and disabling may simultaneously provide comfort, reassurance and hope of recovery.

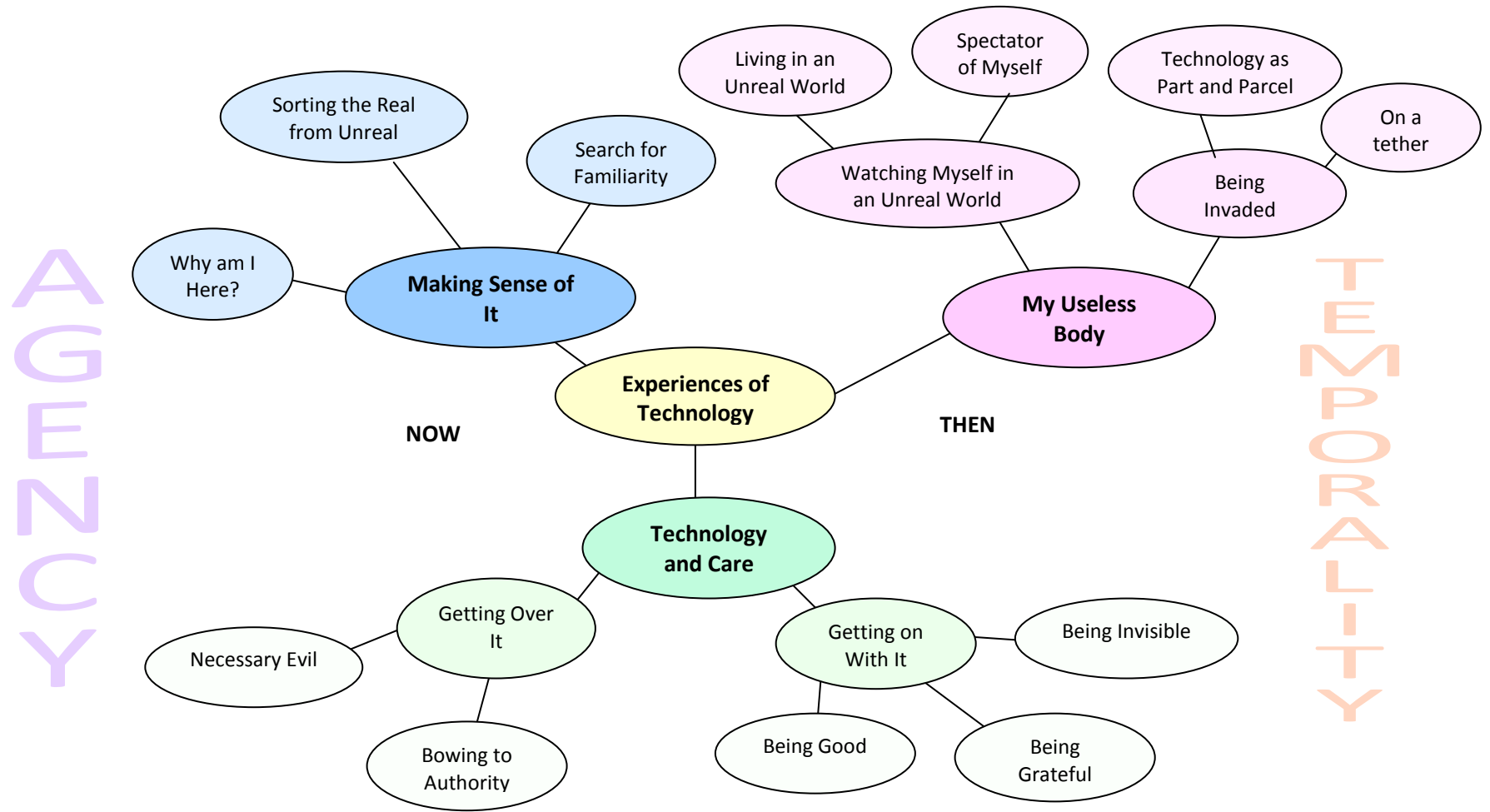


Figure 5: Overall Schema of Patients' Experiences of Technology

Chapter 6: Discussion

Discussion of Findings

Introduction

Participants of this study reported that their experiences of being a patient in ICU as unfamiliar, horrific, petrifying and completely different to their usual known way of being-in-the-world. This confirms the findings of many other studies which describe ICU as unpleasant, terrifying, uncomfortable (Granberg-Axell et al. 2001, Page 175; Johnson 2004), and a traumatic event for patients and their families (McKinney and Deeny 2002; Granja *et al.* 2005; Corrigan *et al.* 2007; Pun and Ely 2007). This study specifically aimed to explore patients' experiences of technology within adult intensive care with the objective of examining patients' perceptions of receiving care in a technological environment and how technology may have influenced their experience of care. The intensive care environment is complex with many potential stressors such as emergency admission to an unfamiliar environment, fear of death or permanent disability, invasive interventions and sleep deprivation (potential stressors and their outcomes were explored in the literature review). The overall context of the complex intensive care environment may, therefore, have had a huge impact on the patient's experiences of technology in ICU. Participant accounts of technology are therefore entwined within these broader understandings. The findings demonstrate the inseparability of experiences from the context within which they occur as participants' accounts of 'My Useless Body' and 'Making Sense of It' constitutes the framework within which their experiences of technology in ICU are embedded. In describing the contextual framework, the participants gave rich descriptions of receiving care within the technological environment and the influence of technology on that care.

An added layer of complexity is the innate physiological impact of critical illness which may result in hypoxia, hypercapnia, electrolyte imbalances, and impaired circulation and may necessitate the administration of drugs and that sedate, invoke hallucinations and delusions, or impair the motor sensory system (Hewitt 2002; Roberts 2004; Granja *et al.* 2005; Ringdal *et al.* 2006; Pun and Ely 2007). In addition to this, participants are often subjected to sleep deprivation and environmental stressors such as extreme levels of noise (Celik *et al.* 2005; Drouot *et al.* 2008; Friese 2008). All of these factors have been associated with the development of perceptual disturbances, impaired memories, and ICU delirium (Ely *et al.* 2001; Hewitt 2002; Celik *et al.* 2005; Friese 2008; Samuelson 2011). Participant experiences may have been influenced and complicated by any one of the above stressors. This study did not aim to rationalise patients' experiences in terms of these physiological and pharmaceutical factors but aimed to illuminate patients' perspective of the experience.

The following section aims to contextualise the findings by drawing comparisons with existing literature. The discussion represents the reported themes however, themes often and inevitably interlink. Some discussion points are therefore multi-faceted and relevant to more than one theme. The participants theme of 'My Useless Body' is discussed drawing on phenomenological writings and current research literature. In doing so the following discussion points emerge: the centrality of the body to the participants' experiences, the notion of the body being not mine, yet mine and the body as disintegrated and invaded. 'Making sense of it' is also discussed with reference to the current body of research. Finally 'Technology and care' is discussed, in particular the inseparability of technology from care, being invisible and lack of agency.

My Useless Body

The centrality of the body

A key essence throughout participants' accounts of their experience of critical illness was their perceptions of their ill body. Participants displayed an amplified awareness of their physicality and associated technologies and paid considerable attention to their physical and functional deficits. Participants' understandings and experiences of care within the technological environment appeared to be founded on the patients' perceptions of their ill body. The centrality of the body to participants' experiences exemplifies the work of seminal phenomenological authors such as Merleau-Ponty, Van Manen, and Sartre.

Merleau-Ponty (1962) discussed the notion of embodiment which recognises that one's own body is not just a thing, but is a permanent condition of experience allowing humans to have a perceptual openness to the world. Our body is essential to experience being-in-the-world (Van Manen 1998). Merleau-Ponty (1962) further declared that one's body is synonymous with existence- we do not have bodies but we *are* our bodies (Wilde 2003; Svenaeus 2011). Zaner (1981, Page 48) clarified that 'My body is not just a tool that I use or a dwelling I live in- it is *me*. I *am* my own body.' Merleau-Ponty further suggested that we are unable to hide from our own body as the body is inseparable from our sense of self. Phenomenology therefore recognises the body as being central to human experience which reflects the predominant role that the body played in participants' accounts of their experience of technology in ICU in this study.

In health we experience our body in a mode of near self-forgetfulness as we engage with being-in-the-world (Van Manen 1998). Sartre (1956) refers to this mode as *passé-sous-silence* (passed over in silence) whereas Merleau-Ponty (1962) describes this as a silent background. However,

during illness the body appears to leave the silent background and enter into our consciousness. As demonstrated by the participants of this study, during illness we have a greater awareness of our bodies and physicality. Whilst Heidegger never specifically wrote anything substantial about health or illness (Ahlzén 2011) consideration of being-in-the-world may offer insight into how the critically ill body is experienced and understand the associated alterations in ICU patients' relationship with their bodies and the world.

Participants framed their understandings of their experiences in ICU with descriptions of their ill body. In particular participants described their failing body in terms of its dysfunction. For example, participants described how they could not breathe, could not stand up, how their arms would not work, and how they could not talk or communicate. As with Heidegger's hammer which when in good repair is used without theorizing, when broken, interrupts the activity and forces us to focus on the broken tool. The hammer goes from being ready-at-hand to being present-at-hand (McConnell-Henry *et al.* 2009). Similarly the body enters our awareness when it malfunctions. Participants who would ordinarily move their limbs and breathe without awareness suddenly become conscious of their lungs, their arms and legs when they malfunction or are weakened by the critical illness. Unlike the hammer, however, the body is not just an object or a tool. The body is integral to our very being, therefore, during dysfunction the fundamental unity of the body and being-in-the-world is broken (Carel 2011). This disruption means that during illness, we are unable to live in a self-forgetful, silent background (Van Manen 1998). 7

Svenaesus (2009a) suggests that illness has a pre-reflective quality- often the dysfunction is not revealed until you try to engage in an activity that requires the fully functioning body. Van

Manen (1998) describes this as a changed physiognomy of the world. The example cited by Van Manen is that of somebody with a broken finger who is reading a book. Whilst the person is reading from the page they are probably unaware of their broken finger. However, when they come to turn the page and require the finger to function, their illness is revealed to them as pain, restricted mobility, and dysfunction (Van Manen 1998). As demonstrated in the findings, participants dispassionately listed their ailments or specific diagnoses but then emotively described their frustration and despair at the dysfunction of basic bodily functions. This changed physiognomy of the world is clearly exemplified in the findings: Participant 12 described how the severity of their critical illness was revealed when they were unable to stand up. Similarly participant 4 did not appreciate how physically weakened they were until they attempted to write a note but were too weak to hold the pen. It is therefore not just the physical body symptoms that constitute illness but also the changed relationship with the outside world. Ahlzén (2011) highlights that illness is experienced as the interruption of the taken-for-granted functionality of the body.

The participants appeared to experience the illness not so much as the disease or diagnosis but more as the resulting impaired function. Participants expressed particular frustration and difficulty in activities that they normally take for granted such as brushing their hair, holding a spoon, washing their face. As Svenaeus (2000a Page 11) observes, the taken-for-granted silence and transparency of normal practical engagement is changed into 'an effortful striving just to get done what is normally performed easily'. In particular, participants focussed on the enforced injuries which often involved technologies such as ET tubes, tracheostomy, nasogastric tubes. Arguably these technologies and enforced injuries have a direct impact on participant's ability to actively engage and function in *passé-sous-silence* (passed over in silence) which makes the

technologies even more prominent in the experience of the critically ill body. Van Manen (1998) describes the patient's experience of this disruption as an encumbrance. The encumbered body is unable to relate to the surrounding world or practically engage in the same way as in health. Participants described the encumbrance of their body by describing it as useless, being a burden and non-functioning. The encumbered body brings about a fundamental alteration to being-in-the-world as it is no longer about practical engagement with the world but becomes about the process of engagement and how that process is impaired.

Body not mine, yet mine

As well as having a heightened awareness of their dysfunctional body, participants within the theme 'Watching myself in an unreal world' described how they felt physically, emotionally and socially disconnected from themselves and their environment. Participants appeared to have a detached and objective view of their bodies. Participants described how they were a spectator of themselves where their body, emotions and behaviours did not feel as though they belonged to them. Van Manen (1998) describes this disconnected mode of experience as The Body of Self as Self-Observed and argues that during illness our body becomes an object of one's own scrutiny where we observe ourselves with a detached curiosity, focussing on the dysfunctional part. Leder (1990) describes detachment of the ill body from self as the dys-appearance of the body whereby the ill body becomes independent from the will and understanding of the ill person. However, as Merleau-Ponty (1962) emphasises, this detachment is never complete as we are never able to separate our body from our sense of self. Our bodies are unique in that one cannot leave your body behind as you can other objects and one cannot see ones' body objectively in the same way you can other objects. The feelings of detachment arguably are

attributable to the fundamental alteration of their being-in-the-world that occurs with an encumbered, critically ill body.

Svenaesus (2000b), influenced by the work of Freud and Heidegger, attempted to characterise the impact of the ill body on being-in-the-world. He suggested that illness evokes '*Das Unheimliche*,' which he described as an unhome-like or uncanny way of being-in-the-world. Unhome-like being in the world infers that we know our world with which we are engaged but at the same time we do not fully know it or control it (Svenaesus 2011). Svenaesus (2011 Page 337) states 'Illness is an unhomelike being-in-the-world in which the embodied ways of being in the self have been thwarted. In illness the body shows up as an alien being (being me, yet not me) and this obstruction attunes the entire being-in-the-world of the ill person in an unhome-like way.' Zaner (1981) influenced by Sartre (1956) also describes the ill body as simultaneously experienced as alien while being themselves. The tension of experiencing the critically ill body as not mine, yet mine is demonstrated in the participants accounts of feeling disconnected from their own bodies, emotions and behaviours yet it still being them. For example, Participant 6 described how that despite seeing their own hand, moving it, feeling it, it still didn't feel as though it belonged to them. Participants rationally knew that their body was theirs yet it still felt alien or foreign to them. Participants described how it was like watching themselves in a movie or in a play. Within this study, the process of alienation is not just restricted to physical sense of the body but also their emotions and behaviours where participants described extremes of emotions that were foreign to them and behaviours that were uncharacteristic to them. This has not previously been specifically demonstrated in other reported research literature. Granberg *et al.*'s (1998) participants reported feeling as though their body was alien but only referred to the physical aspects such as arms feeling like lead however, no emotional and behavioural aspects

were reported. Russell (1999) and Hofhuis *et al.* (2008) reported that participants often felt embarrassed by their behaviour whilst in ICU but did not suggest that they felt separated or disconnected from it.

The level of disconnection from their bodies, emotions, behaviours and the surrounding environment described by the participants of this study shares some similarities to trauma related dissociation. Dissociation is an automatic psychological response to overwhelming emotional pain or trauma (Friedman *et al.* 2007). Dissociation is most commonly experienced as a subjective perception of one's consciousness being detached from one's emotions, body and/or immediate surroundings where the usual synchronous elements of the psyche such as awareness, memory consolidation and mood regulation lose their usual integrated function (Dell and O'Neil 2009). Manifestations of dissociation include depersonalization, where the person may feel detached from the self or body, and derealization, where the person may feel detached from their world and environment with distortions of space and time (Van der Hart *et al.* 2004; Dell and O'Neil 2009). Dissociation during traumatic events is known as peri-traumatic dissociation and is thought to serve as a protective or defensive function at the time of trauma. In this sense it is frequently viewed as an adaptive process or a means of coping. However Ozer *et al.* (2003) and Gershuny *et al.* (2003) have demonstrated that the presence of peri-traumatic dissociation has been found to be predictive of later distress including PTSD. Dissociative processes are also associated with trauma-related memory impairment (Friedman *et al.* 2007). Participants' expressions of disconnection from themselves and their environment by no means constitutes a definitive diagnosis of trauma related dissociation, it does however indicate the extent of the potential emotional and psychological trauma associated with being a patient in ICU.

The Disintegrated Body

Phenomenological authors such as Van Manen (1998), Svenaeus (2000a; 2000b; 2009a; 2009b; 2011), Merleau-Ponty (1962) all describe the alienation of the ill body and discuss how the body and its processes become objective entities. From examination of the participant data the critically ill body goes beyond being objectified or alien as it becomes fragmented and disintegrated. In describing their experiences participants often focussed on the diseased body part describing it in disintegrated, decontextualized fragments. Organs were frequently described in isolation; 'my collapsed lungs', 'lacerated liver', 'kidneys' perhaps indicating that they were separate things, not just separate from their sense of self but as though they were separated from the rest of their physical body. As demonstrated by this study, Marcum (2004) theorized that the ill body may be fragmented into biomechanical parts. Many participants made sense of their experiences and construed their illness in terms of deconstructed, diseased or dysfunctional body parts. Participants' sentiments of having a disintegrated body are echoed in many studies that examined experiences of patients in ICU (Granberg *et al.* 1998; Granberg *et al.* 1999; Johansson and Fjellman-Wiklund 2005). In Gjengedal *et al.*'s (2010) study patients described themselves losing contact with their own bodies and expressed feelings of separation from the diseased body parts. Johansson & Fjellman-Wiklund (2005) revealed that ICU patients frequently described their own body parts, in particular their limbs, as 'things' and felt that they were disassociated from the rest of their body.

Another feature of critical illness is the overt presence of life-supporting technologies which is not comprehensively considered in Van Manen's, Svenaeus and Merleau-Ponty philosophical accounts of the ill body. Technology may further objectify and fragment the body as it makes the normally invisible become visible. For example, breathing is normally a subconscious activity

whereas the presence of an endotracheal tube, tracheostomy and mechanical ventilator both brings breathing to the forefront of consciousness and objectifies the process into discrete physiological measurements such as blood gases, oxygen saturations, and respiratory rate. Participants within their accounts frequently described their own breathing in terms of these discrete measurements referring to low oxygen levels, breathing too fast- factors that in health they would neither be aware nor consider. Similarly, participant 11 described his revulsion of the nasogastric tube and collection bag which drained the contents of his stomach. As well as his obvious distaste, he stated that it made him feel as though he was 'falling apart'- his body disintegrating as what is normally concealed is revealed. Reventlow *et al.* (2006) suggests that technology reduces the body to organs, fluids, bodily states which promotes self consciousness and self surveillance. Marcum (2004) also suggests that rather than being an embodied person the patient becomes a collection of test results derived from the employment of medical technology. Within the data participants appeared to adopt health care professional vernacular and frequently referred to their objectified, body measurements such as 'irregular heart rate', 'blood levels'. Participants often seemed to rationalise their critical illness experiences in relation to these physiological measurements.

Participants, within their accounts, appeared to formulate many understandings of their experiences in relation to their disintegrated body. The disintegrated critically ill body appears to be the focus of the critically ill person's attention. In other words their suffering body is central to all of the critically ill persons' perceptions, experiences and understandings, and most significantly their being-in-the-world. The disintegrated and fragmented body arguably surpasses the unhome-like experience of the ill body as described by Svenaeus (2011). The disconnection of the participant with their body and their relationship with being-in-the-world is

so great that their whole perception and engagement with the world is altered on every level. The critically ill body becomes such a source of pain and such an obstacle to ones everyday engagement with the world making being at home with one's body difficult if not impossible. Zeiler (2010) too suggested that the ill cannot concentrate on anything else other than the body in pain. It is worthy to note that participants within this study seldom referred to physical pain whilst in ICU. This is consistent with the findings of other similar studies (McKinley *et al.* 2002; Johnson 2004) where patients in ICU frequently reported discomfort but rarely physical pain. Therefore by pain, I refer to the epistemological pain described by Van Manen (1998, Page 8) 'The painful body is not a body constantly in pain; rather, it pains when I try to do something that I am unable to do'.

The disintegrated body is so great an encumbrance that there is an impossibility of retreat (Zeiler 2010). Scarry (1985) suggested that extreme pain and suffering may obliterate the contents of one's own consciousness where the pain becomes the whole being-in-the-world. Despite discussing the experiences of victims of torture, Scarry's (1985) observations mirror participants of this studies experience where participants' lose their sense of self to the pain and suffering of the deconstructed body. The disintegration and dysfunction of the body is so extreme that even the most basic bodily functions are impaired and come to the fore. At the most fundamental level, the silent background is reversed- the silent background becomes a roar.

The invaded body

Participants described how technologies were enforced upon them. In particular participants recall the presence of tracheostomy tubes, endotracheal tubes, nasogastric tubes and central

venous catheters. Enforced technologies during critical illness are inevitable. Once disintegrated, the failing organ or body part's function is frequently supported or replaced by health care technologies. Lock (2004, Page 158) identified that technology in affect is a 'simulacrum for the functioning of the dysfunctional body part'. Technologies therefore take over involuntary tasks which patients are no longer able to perform independently. As such the body is dependent on technology and a patient's existence is determined by technology. Marcum (2004) suggests technology may contribute to the objectification of the body where the patient's body parts become 'cogs in a medical machine world'. Health care professionals may then manipulate the objectified body part with technology leading to disembodiment of the patient. The significance of this disembodiment is discussed in more detail in a later section entitled 'Being invisible' within the theme of 'Technology and care'.

Despite describing how they felt physically detached from their bodies, participants within this study described how their disintegrated body, in the presence of technology, felt invaded and tethered suggesting a sense of self on some level. This further exemplifies the notion of the critically ill body being not mine, yet mine. Phenomenological authors have attempted to clarify the nature of the body and made a distinction between what Van Manen (1998) refers to as the physical body and the lived body. Merleau-Ponty refers to the physical body as *le corps objectif* and the lived body as *le corps propre* (De Preester 2011). The physical body is described as being the biological and mechanical body, the objective body of medicine whereas the body lived is the first person experience of this objective body. In health, Carel (2011) suggests that the two are aligned in harmony. The tension of the participants body being not mine, yet mine may indicate a disharmony between the physical and the lived bodies during their critical illness. Participants may have felt disconnected from their *corps objectif* but remained engaged with

their *corps propre*, which they felt was being invaded- invaded by both abnormal additions and extensions to the body (technology) and also by diseased or damaged body parts and organs.

Participants within this study demonstrate a further perceptual tension as they described experiencing technology as being an invasion as well as describing it as being subsumed into their body, being as participant 2 describes 'part and parcel'. Participants frequently described the blurred boundaries where their experience of their body extends beyond that of their physical body. For example, participant 6 felt as though the ventilator alarms were part of him and his critical illness. Another participant described how they felt as though they had become part of the bed. Other authors investigating experiences of patients in ICU report experiences of blurred body boundaries. Johansson and Fjellman-Wiklund's (2005) study described how participants found it difficult differentiating between the body and their technological surroundings. Other studies have revealed a distortion in body image where technology has become subsumed into the patient's perception of their own body (Lapum *et al.* 2010). It would appear that in ICU, technology can merge with the biological. Marcum (2004) suggests that the ill body with technologies applied strives to incorporate modifications of and additions to the body into their unique life-world. During critical illness, as demonstrated by the participants of this study, it would appear that embodiment can be stretched to include the artificial enhancements of, or additions to, the body.

Technologies may be considered comparable with Heidegger's tools. According to Heidegger, tools such as his hammer, when used successfully become ready-to-hand, or quasi-transparent. When a tool is ready-to-hand we focus on the activity with which we are engaged rather than the tool or technologies that we are using to perform the activity (De Preester 2011). Applied

tools or technologies therefore may feel as though they are part of the embodied self. Similarly, participant 3 describing the vacuum wound dressing as being part of him was perhaps experiencing the vacuum dressing as ready-to-hand. During successful and unencumbered use, technologies become a knowing part of the participant's body where they withdraw into the body actively engaged with practical activity. Technologies are therefore not inert supplements to the body. Despite this successful use of a tool or technology, De Preester (2011) argues that you do not have the same sense of ownership as you do your own body. The example she uses is using a fork to eat your dinner- the tool becomes integrated into the body and the eating process but you do not feel a bodily ownership of it. Therefore technologies may extend the body, feel subsumed into the body yet still not be completely integrated into one's own body. This may explain why participants of this study described a tension between simultaneously experiencing technology as an invasion and as being part and parcel with their body.

Summary

Phenomenological authors, influenced by both Husserl and Heidegger, such as Merleau-Ponty (1962), Sartre (1956) and Van Manen (1998), and more recently Svenaeus (2009, 2011a) have attempted to develop unique phenomenological models of illness and the ill body. Within these authors' commentaries, however, there is no specific reference to acute, critical or life threatening illness. Most commonly they refer to chronic or mental illness. This thesis is the first investigation to utilise the acute ICU setting. Despite this, insights from the phenomenological perspective of the body support and explain some of the experiences of a 'Useless Body' described by the participants of this study. In particular the centrality of the body to human experience is demonstrated in this study. The participants focus on the ill dysfunctional body is also akin to Van Manen's notion of the 'body of self experienced as encumbered' (Van Manen

1998, page 6). Participants also described how their dysfunctional body resulted in an altered practical engagement with the world as suggested in the phenomenological literature. The alienation of the ill body suggested by Sartre (1956) and the tension of the body being both alien yet mine are all reflected within the participant's accounts.

My initial assumption about the phenomenology of the ill body was that the experiences of the critically ill body would be the same but perhaps amplified. However, upon analysis of the literature and participants' accounts it would appear that experiences of the critically ill body invaded by technology do share some features of the less acute or life threatening ill body whilst displaying some unique features. To date, phenomenological models of the ill body do not exhaustively explain the experiences of the disintegrated, critically ill body in an intensely technological environment. Neither have they taken into account the intense and very real fear of losing one's life or facing a permanent disability. As such, current phenomenological models of the ill body do not comprehensively explain the experiences of the participants of this study.

This study begins to resolve some of the highlighted deficits. The critically ill body is beyond unhome-like and is experienced as disintegrated. The disintegrated body is not just the focus of the critically ill person's body as with the broken hammer, it becomes everything. It over rides and eclipses other understandings. Everything that normally exists in the taken-for-granted silent background comes to the fore and makes a deafening roar. Therefore the critically ill body dominates being-in-the-world. This study in particular demonstrates the severity of patients' experience of their ill body which appear to form the basis to their understandings of why they were a patient in ICU.

Making sense of it

Constructing a story

Making sense of their experiences in ICU appeared to be fundamental to participants' understandings and subsequent accounts of technology in ICU and being cared for in a technological environment. Participants within this study spent time making sense of their experiences and constructing a story that was understandable to them. It appeared that experiences of technology could only be revealed by making sense of their overall experiences of ICU and describing them in an integrated meaningful story. All participants were eager to share their sometimes painful and traumatic memories of ICU. My initial question asked participants to describe the events leading up to their ICU admission. Many participants would then progress on and tell the rest of their story with very little prompting only stopping to clarify details or to double check the chronology of their tale. The eagerness of patients who have been in ICU to describe their experiences has been reported in other studies (Hupcey and Zimmerman 2000b; McKinney and Deeny 2002; Williams 2009; Williams 2010). Williams (2009) conducted a hermeneutic study of five patients one year after discharge from ICU and suggested that there is a therapeutic or cathartic benefit to constructing and telling their story. Other authors have also theorised that constructing a cohesive and meaningful story may facilitate the psychological recovery of the patient (Hupcey and Zimmerman 2000b; Corrigan *et al.* 2007).

Williams (2009) clarified the potential benefits of enabling ICU patients to construct their own illness narrative suggesting that stories may create order out of chaotic or fragmented memories which is necessary for personal orientation and peace. In addition Williams (2009) highlighted that constructing a story may stabilize the patient's sense of self which might have been de-stabilised by the life threatening event improving the patient's ability to cope with the

traumatic event. McKinny & Deeny (2002) found that patients were eager to cognitively revisit their ICU experience in an attempt to re-frame their experiences and restore a sense of meaning. Similarly Corrigan *et al.* (2007) and Engstrom *et al.* (2008) also suggested that patients have a need to make sense of and find meaning in their traumatic memories.

For participants in this study giving a chronologically accurate account of the events and experiences seemed to be very important. Several participants spent a great deal of time making sure that they were re-telling the story in the order in which events happened. Many sought clarification from relatives if they were present during the interview. One participant even double checked in their pocket diary to make sure that they were telling me the correct time and date that they were discharged from ICU. It appeared that participants needed something tangible, a universally understandable concept such as time, on which to hang their experiences and formulate their understandings. Williams' (2009) qualitative study which investigated the impact of hospital critical incidents on patients also found that the temporal coherence of the story is very important to the patient who is constructing their illness narrative. A story demonstrates temporal coherence when it has a logical and consistent chronology (Williams 2009). The nature of critical illness means that the patient may spend expanses of time when they are unconscious. There will therefore be spans of time where patients have little or no memory. Participants within this study described how they felt they had lost days or weeks which they described as disorientating. Participants' memories of events and experiences therefore did not necessarily correspond to a chronological timeframe. Seeking a chronologically accurate story may have been the participants' attempts at re-orientating themselves and re-claiming the lost time by accounting for it day by day, hour by hour, and minute by minute.

Previous studies (Hupcey and Zimmerman 2000b; Corrigan *et al.* 2007; Williams 2009) have investigated patients at a later stage in their recovery (at least one year post ICU discharge) in contrast to this study which interviewed patients 3-7 months after discharge. It is interesting and pertinent to note that participants value a meaningful and temporally cohesive story early on in their recovery process.

Memories

All study participants demonstrated having memories of their time in ICU. I was surprised at the level of memory of all of the participants as from my professional experience I felt many ICU patients display very little memory of their ICU admission. In addition, the literature suggests that amnesia is common for the ICU period and often for the entire hospital admission (Jones *et al.* 2007; Samuelson *et al.* 2007; Kiekkas *et al.* 2010). Ethier *et al.* (2011) suggest that 29% to 48% of patients in ICU have no recall of specific ICU events. The unusually high level of memory within this study group may be due to the self-selecting nature of recruitment utilised- potentially only patients who felt that they have an adequate memory of their experiences would volunteer to participate in a study that asks them to describe their experiences. Interestingly, many participants initially claimed to have little memory of ICU but then recounted vivid, detailed and intricate memories with little prompting. Granberg *et al.* (1998) described a similar occurrence with the participants of their qualitative study investigating the experiences of ICU patients.

All participants were able to describe factual memories of particular events or occurrences. Many described memories of specific events such as visits from family members or friends, care interventions involving technologies such as endotracheal suctioning, having blood taken, drug

administrations, the presence of intravenous and intra-arterial lines and monitoring devices. Others remember being moved in bed, and physiotherapy and conversations with health care professionals. Roberts et al (2007) in multi-centre cohort study suggested that most patients (83%) in ICU have factual memories of their stay. This finding is supported by Ringdal *et al.* (2006) who also found that 83% of patients demonstrated having factual memories. Participants in this study often described having 'patchy' memories where their factual memories were punctuated with gaps where they had no memory at all or were only able to recall hazy or incomplete memories. Participants' clear memories were often of certain events such as family visits, technological procedures and interventions however, participants were often unable to clearly describe their surroundings or the staff caring for them. A number of participants even described staff as invisible or faceless which is discussed in more detail in 'Technology and care' section. The significance of this previously unreported finding is unclear. However, fragmented memories have been demonstrated in other studies (Löf 2006; Jones *et al.* 2007; Storli and Lind 2009). Patients have been described as having 'memory gaps' (Griffiths and Jones 2011), or 'jigsaw puzzle' memories (Granberg *et al.* 1999).

In recalling their memories and constructing their story, participants frequently reported frightening delusional, often paranoid memories, hallucinations and nightmares. In describing their distorted memories, participants were often very apologetic and embarrassed. Participants frequently started their recollection with 'You will think I'm daft...' (Participant 6), 'I know it sounds weird...' (Participant 12), 'I know this is totally wacky...' (Participant 16), 'I was obviously going mad...' (Participant 4). Participants often required encouragement and reassurance that distorted memories are common in ICU patients before they would proceed in their accounts. Interestingly, participants were able to continue and give very clear and detailed descriptions of

their distorted memories, dreams and nightmares. Participants in other studies have also expressed embarrassment at their behaviours and confusion (Hupcey and Zimmerman 2000b; Corrigan *et al.* 2007; Hofhuis *et al.* 2008). The data illustrates that delusional memories, hallucinations and altered perceptions are a key feature within the findings. This has been corroborated many times in the research literature (Granberg *et al.* 1998; Granberg *et al.* 1999; Russell 1999; Magaray and McCutcheon 2005; Lof *et al.* 2006; Roberts *et al.* 2006; Almerud *et al.* 2007; Roberts *et al.* 2007; Jones *et al.* 2010; Griffiths and Jones 2011). In their study of trauma patients, Ringdal *et al.* (2006) found that up to 26% of participants questioned reported delusional memories including hallucinations, nightmares and dreams.

As with other studies (Russell 1999; Magaray and McCutcheon 2005), participants' hallucinations and delusions were often of a persecutory nature with participants describing how they felt that health care professionals were trying to deliberately harm and torture them. The surrounding environment and technologies often formed part of the participants' hallucinations and delusions. Papathanassoglou & Patiraki (2003) identified that fragments of stressful experiences may be symbolically incorporated into dreams and hallucination content. Many participants described feeling as though they were in a war zone or in the midst of a global crisis. Similarly, Russell (1999) described how her participants described scenes of war and fighting. Skirrow *et al.* (2002) report that media coverage of war situations and global affairs can influence the content of ICU patients' dreams and hallucinations.

At the heart of all of the delusions and hallucinations experienced by the participants of this study was overwhelming anxiety. Fear was often centred on suffering and as previously discussed, their dysfunctional body. Participants described intense anxiety and stress

particularly when their peculiar experiences could not be rationalised. Anxiety and stress is also reported widely in other literature (Adamson *et al.* 2004; Magaray and McCutcheon 2005; Jones *et al.* 2007; Hofhuis *et al.* 2008; Löf *et al.* 2008). The extreme levels of stress and anxiety experienced whilst in ICU is significant as it may lead to many physical and psychological sequela (Papathanassoglou and Patiraki 2003; Sukantarat and Brett 2007). Papathanassoglou *et al.* (2010) highlights that stress neuropeptides such as corticotrophin releasing hormone (CRH) adrenocorticotropin hormone (ACTH) substance P and prolactin, are released from the central nervous system in response to both physical and emotional stressors and these stress neuropeptides may lead to immunosuppression and exacerbate cellular inflammatory response. In turn physical recovery may be impaired and both length of stay in ICU and hospital may be increased (Kiekkas *et al.* 2010).

Participants recall therefore appears to be a complex mix of factual memories, missing or hazy memories, delusions and hallucinations. In making sense of their experiences and constructing their story participants attempted to sort the real from the unreal. Participants described how they had sometimes had difficulty in knowing what were real memories and which ones were dreams, delusions or nightmares. This was further complicated when real life events, people and objects entered into the participants dreams and nightmares. Participants described how reality and unreality were intermingled and inseparable. Other research studies have revealed similar complexities in patients' recall of ICU (Russell 1999; Jones *et al.* 2001; Corrigan *et al.* 2007). Storli *et al.* (2009) described patients' memories as chaotic mixtures of real events, dreams, hallucination and amnesia. Magaray and McCutcheon (2005) described how patients moved in and out of reality along a continuum and similarly, their patients reported difficulty in distinguishing between the two. Much like the participants of this study, Magaray and

McCutcheon (2005) also described how patients reach a point in their recovery where they are grounded in reality and finally able to rationalise that their delusions, dreams and nightmares are just that. This point was often associated with physical recovery. Many participants in this study described a definite point in time after which they appeared to have clear recollections and where suddenly everything started to make sense. With a study of this nature it is impossible to detect if there were any common factors of when and how individual patients reached this moment of revelation and what if anything practitioners could do to support patients in reaching this stage. However, within the participant discourse their appreciation of accurate information regarding their condition and what had happened to them as well as reassurance for their future continued recovery was evident.

Participants demonstrated how they attempted to sort real memories from the unreal. Participants expressed anxiety at not knowing if certain memories were true. Some participants found this process difficult as it appeared that real events were incorporated into their unreal memories. The process of sorting memories demonstrated by the participants is significant as the importance of having factual recall in the patients long-term recovery and well being has been demonstrated in the literature. Ringdal *et al.* (2006) and Griffiths and Jones (2011) identified that patients with continued adverse and delusional memories reported lower quality of life, increased anxiety and depression and may even be predictive of later PTSD. In addition, Jones *et al.* (2001) postulate that clear factual memories may offer protection against the development of PTSD. Griffiths and Jones (2007) suggest that factual memories enable patients to recognise that their delusional memories are not real and therefore rationalise them. Participants within this study did indeed describe how they attempted to rationalise their unreal or delusional memories with more factual memories. For example participant 9 recognised that

the presence of a lady feeding blood to her feral daughter was improbable given that they knew that they were in hospital. Participant 16 who despite being convinced that they had seen Benjamin Zephaniah rationalised that such a famous poet would probably not be working in an ICU in the UK.

Whilst the importance of sorting the real from the unreal has been clearly demonstrated in the literature, little is written about how and when this process occurs. Consideration of the findings begins to demonstrate how patients approach the process of sorting the real from the unreal.

Filling the gaps

Participants in this study frequently described gaps in their memories and knowledge of their stay in ICU. Gaps in memories varied from being hazy over some details to having no memory for several days. Most participants expressed frustration at not having a clear memory of events; two participants however suggested that they felt they were better off not knowing. These two participants suggested that they were glad they couldn't remember as both had confined their critical illness 'to the past' and one said that they preferred not to dwell on things and wanted to move on with their life. Most participants however were eager to find out exactly what had happened to them and described how they relied on members of their family to 'fill in the gaps'. Gathering information from their family members seemed important for the patient constructing and making sense of their story. The reliance on family members to fill in their memory gaps has only been tentatively acknowledged in previous literature (Hupcey and Zimmerman 2000b). However, the findings of this current study emphasize the family as an important information resource for the patients suggesting that participants found family accounts accessible and meaningful. Participants appeared to be seeking what Williams (2009)

describes as causal coherence where events are presented in such a way that makes sense- in other words it explains why events turned out the way they did. Once the missing information had been gathered, participants demonstrated how they integrated their own memories with facts provided by family and health care professions in order to construct their story.

Summary

The need to formulate an understandable and meaningful story early in their recovery process has been clearly demonstrated within this study. This need has only previously reported in patients at least one year post discharge. As well as the importance of constructing a story this study gives a preliminary insight into the mechanisms and processes by which the patient recovering from critical illness constructs that story, which has not previously been reported in the literature.

Memory recall appears to be patchy and a mixture of memory of real events, hazy memories, delusions and hallucinations which is also reflected within the literature. Technology as an unfamiliar presence within a strange environment was clearly present in participants' memories. As well as having factual memories of specific technological interventions, on occasions, technologies appeared to be incorporated into patients' delusions and hallucinations. Whilst participants recalled technological procedures and events, memories of staff and their environment seemed poor with staff being described as invisible or faceless. This has not been previously reported in the literature.

Participants' often harrowing memories, delusions and hallucinations appeared to demonstrate intense levels of fear, stress and anxiety, which according to the research literature may impair

patients' physical and psychological recovery from their critical illness. Participants in this study demonstrated that they attempted to sort their real memories from the unreal. The importance of factual or real memories has been highlighted within the literature however there are no reports regarding the process by which patients rationalise their factual memories and their delusions and hallucinations. This study reveals that patients gather information about their stay in ICU. Some participants mention discussing their stay with members of staff however, mostly participants spoke to their family. The participants in this study appeared to emphasize the importance of their family in helping them to fill in their memory gaps and rationalise their memories. Participants then integrated their own memories with the received information to construct a coherent story. Families have been identified as an information resource for ICU patients (Hupcey and Zimmermann 2000b) however their importance in helping patients to construct their story has not previously been reported.

Technology and Care

Consistent with the phenomenological approach patients' experiences of technology and care are inseparable from the overall intensive care context. Participants constructed understandings of technology are therefore enmeshed within the unified framework of 'My Useless Body', 'Making Sense of It' and other broader understandings such as the social, historical and cultural contexts. For clarity and ease of discussion, themes relating specifically to technology have been teased out, however, it is important to acknowledge that participants presented them as a unified, multifaceted experience. The following discussions address the objective of explicating patients' experiences of care in a technological environment. This theme provides a unique view as there is very little published research that reports the patient's perspective of technology in

ICU. The reported findings are therefore often compared to research that conveys the perspective of healthcare professionals.

Inseparability of technology and care

Within the participant data there exists a tension in how participants perceive technology and care as participants describe technology and care as being inseparable yet at the same time describe specific instances of non-technological activities that they describe as 'nursing care' inferring that these activities are somehow separate or different from technological interventions. This tension is explored in the following section.

Participants appeared to reject the Cartesian dualistic distinction of technology 'and/ or' care and demonstrated that they experienced technology and care as a unified encounter. Participants did not separate the management of technology from the overall care that they received. Moreover, it appeared that participants took the application of technologies for granted in ICU and recognised technology as being essential to their care and recovery.

As discussed within the literature review there are several key studies that investigate technology and care from the care givers perspective which suggest that technology and care are inseparable; Ray as early as 1987 first described the notion of technological caring suggesting that technology and care were harmonised in daily nursing practice (Ray 1987). Locsin (2010) and Little (Little 2000) describe the application of technologies in ICU as an expression of caring whilst Wikström *et al.* (2007) described technologies as an integral tool to a nurses' work. Indeed McGrath (2008) described how ICU nurses embraced technology such that it was *ready-at-hand*. It would appear that at least in part, patients agree with the nurses' view

that technology becomes an inseparable component of the totality of the caring process within critical care.

Conversely, when specifically asked about nursing care, participants focussed on non-technological aspects of care such as personal hygiene, providing drinks and emotional support as though nursing care was something separate to technology. Participants within this study seemed to view technological interventions such as endotracheal suction, venepuncture, drug administration as something different to what they perceive to be 'nursing care'. It appeared that participants described technological interventions that perhaps caused them discomfort or inconvenience as necessary procedures or treatments rather than 'care'. The patients perception of caring seems to be understood more in terms of personal, physical and emotional comfort and support.

Although not specifically investigating the meaning of care, a number of qualitative studies reveal that ICU patients greatly value personal care. Hofhuis *et al.* (2008) identified that patients within their qualitative study placed great importance on personal, humane care such as holding hands and communicating with the nurse. Cypress' (2011) study highlighted that patients in ICU felt that physical care and comfort was one of their priority needs and valued bathing, oral care and comforting touch. It would seem that ICU patients' perceptions of nursing care are consistent with social perceptions and lay or media images of nursing where nursing care is often perceived as providing comfort, emotional support (Belcher 2003) and tending to hygiene needs (Cutcliffe and Wieck 2008). Conversely treatments and interventions are often socially perceived as the domain of the medical profession (Timmermans 1998; Meier 1999). Arguably this tension does not necessarily discount the notion of 'technological caring', but in describing

the personal, non-technological elements of care participants are merely highlighting the episodes of care they perhaps found most comforting and meaningful. It would appear that participants' perceptions of care as focussing on emotional support and comfort are therefore aligned with the existential theories of care (Spichiger *et al.* 2005) which emphasize the interpersonal relationship between nurse and patient.

As well as perceiving technology and care as inseparable, participants frequently viewed nurses as being integrated with the surrounding technology. Nurses, and other health care professionals, were encapsulated within the process of applying technologies such as tracheal suctioning, intravenous drug administration, and venepuncture. Participants described 'faceless' or invisible care where participants were able to clearly describe the care activity but have no memory of a person delivering it. Almerud *et al.* (2007) who qualitatively examined patient experiences of ICU also demonstrated that patients perceive the caregiver as being an extension of the machine. In a sense the nurse, the technology and the care become phenomenologically transparent- they are ready-to-hand. The nurses as the faceless operators of technology arguably demonstrate the potential 'danger of modern technology' as discussed by Heidegger in his seminal paper 'The Question Concerning Technology' (Heidegger 1977). The key concepts of Heidegger's philosophy of technology are difficult to understand which is further complicated by the multiple translations and interpretations however, I have attempted to apply Heidegger's key tenets to the use of technology in ICU.

All technologies have an essence (meaning) which is concealed to people, however, the essence of the technology is only unconcealed (Bringing-forth) when there is a demand for its use (Waddington 2005). Heidegger (1977) suggests that the essence of modern technology is *Gestell*

or enframing which he describes at length in his paper. Despite the lengthy definition, the language is impenetrable and is not forthcoming with a succinct and easily understandable definition- as Waddington (2005, Page 567) suggests, 'reading Heidegger is like trying to navigate a ship through dense fog'. However, O'Brian (2004) describes *Gestell* (enframing) as a mode of human existence that describes the way in which humans relate to modern technology. Brassington (2007) characterises enframing as a mode of revealing the world which reduces things to their constituent parts which may then be manipulated. Enframing is also the striving after efficiency for efficiency's sake (Bennett 2011). Heidegger exemplifies enframing by suggesting that in the presence of a hydroelectric plant, a river ceases to be a river but once enframed by modern technology is viewed as a source of power (Heidegger 1977).

Heidegger suggests that modern technology poses a threat or danger to humanity as whilst being enframed by technology, humans may become oblivious to other modes of being (Brassington 2007). Technological enframing has the potential to alienate the world by reducing it to a 'standing-reserve' or a collection of resources at humans' disposal for the achievement of efficient productivity (Bevan 1998) much like the river being viewed solely as a source of hydroelectric power. Humans themselves may be viewed as a standing-reserve or in the words of Brassington (2007), 'a walking store of human-stuff and potential economic productivity'. Therefore in reducing this rich world and the humans within it to standing-reserve, technology implicitly discounts or at least diminishes humanity- therein lies the danger.

An example of enframing as described by Bevan (1998) is when a nurse may monitor the machine and the patient in an unseeing ritualised manner. The technological demand numbs the 'Being' of the nurse and the 'Being' of the patient. The technique of monitoring is performed

because that is what is required- hence the nurse is caught in technological essence or enframed. Arguably nurses in ICU are so enframed by technology that they too disappear behind the technology; they are catering to the demands of technology to ensure efficient productivity. Bennett (2011) proposes that the nurse who is technologically enframed may not have an awareness or understanding of the omnipresence of technology. Bevan (1998) theorises that the enframing of nursing may cause a decline in the craft of nursing (Bevan 1998). Heidegger (1977) suggests that a craft is to be understood by its relatedness to its materials and without relatedness the craft will only be empty busy work (Bennett 2011). By becoming enframed the nurse (craftsperson) who is nursing (craft) is in danger of losing the relatedness of her work- that of caring for the person (Bevan 1998). The essence of technology is not just technological knowledge and know-how, it is also the awareness of its essence and everywhere-ness. Arguably, therefore, participants may perceive care in ICU to be faceless or invisible because the nurse is so enframed by technology that the craft (nursing) has lost its relatedness. In other words the nurse is so concerned with the direct outcomes or efficient productivity of technological intervention that they have lost sight of the humanness of the patient. The data from this study, as will be examined later in this discourse does not fully support this postulation to the extreme degree inferred by Heidegger as the nurses engagement with the world and their patient is far more complex since the outcome of the technological productivity is the preservation of humanity and life.

Furthermore, consideration of the nurse as enframed by technology is only considering one half of the equation as it is not just the health care professional who may be enframed by technology- the patient may also be enframed. Whilst the nurse may have a narrowed appreciation of the essence of technology so too might the patient. In their critically ill

condition, dependent on surrounding technologies for their survival, patients in ICU will have their own mode of being (*Gestell*) with technology. The enframing of patients by technology will almost certainly influence their perceptions and experiences and perhaps narrow their field of appreciation for the relatedness of the craft- in other words the nurses and nursing care. Perhaps then, care appears to the patient as faceless or invisible because for them the function of technology presides as their survival and wellbeing depend upon it.

Within the literature review the presumed tension that exists between technology and caring was discussed. There is also a suggestion that the presence of technology marginalizes care and diverts the nurse's attention away from the patient (Barnard and Gerber 1999; Bunch 2002; Lee 2004). Other authors suggest that technology dehumanises, depersonalises and fragments care (Clifford 1995; Walters 1995a; Barnard and Sandelowski 2001). These suggestions are largely based on theoretical and philosophical musings, or derived from data collected from the nursing perspective. Given that the participants view technology and care as inseparable, at first sight it would appear that the participants' perspective refutes the tension between technology and care, however, it is not so straightforward. Instead, the data highlights a tension or paradox where despite experiencing technology and care as a unified encounter, participants also describe times when care was impersonal and fragmented due to the presence of technology. The following section explores this paradox in more detail.

Being invisible and grateful

Participants described feeling invisible whilst in ICU and described episodes of impersonal care where caregivers seemed more interested in the monitors and surrounding technology than the patient themselves. Participants also described how they felt lonely and isolated in the presence

of technology. Feeling invisible in ICU, is a sentiment that is reflected in other research literature (Almerud *et al.* 2007; Lapum *et al.* 2010). The role of technology in the disintegration and alienation of the critically ill body has already been discussed in an earlier section however technology may also contribute to patients' feelings of invisibility. Lapum *et al.* (2010) suggests that patients undergoing cardiac surgery may disappear behind technology whilst Bergbom and Askwall (2000) who investigated patients receiving mechanical ventilation suggested that they may not be viewed as individuals potentially leading to feelings of isolation. Almerud *et al.* (2007) suggest that patient's feel like objects of clinical vigilance whilst being invisible at the personal level. This is echoed in this study as despite being constantly monitored and observed by health care professionals, participants described feelings of isolation and loneliness. As participant 4 of this study poignantly describes, they never felt as though they had so much attention yet felt so neglected- or as Almerud *et al.* (2007, page 157) suggested 'being of vigilance and invisibility'.

Participants of this study described invisible care where they were conscious of activities going on around them but did not know exactly what was happening. Participants described nurses doing things to them but them not understanding what was being done and why. Further to the patient being eclipsed by technology, this also suggests a problem with communication where participants were either not given or could not remember any explanations. This perceived lack of communication seemed to contribute to the paranoia and confusion of some of the participants. Distress such as frustration, isolation and confusion caused by poor communication in ICU has been described in other studies (Russell 1999; Magnus and Turkington 2006). Communication difficulties are rated by patients as being the stressful and are commonly associated with anxiety, sleeplessness and distress (Rotondi *et al.* 2002; Kiekkas *et al.* 2010).

Communication affects the quality of patients' experiences as effective communication may reduce anxiety in ICU patients (Happ *et al.* 2011). Healthcare professionals, however, face a challenge as to how much information to give at what time in light of patients varying levels of consciousness, presence of sedative and psychogenic drugs. Indeed some participants in this study admitted that they felt that they were not able to comprehend all that was said to them. Other participants suggested that they might have forgotten explanations that were given. Patient participants in Magnus and Turkington's (2006, Page 175) also suggested that they would not have understood explanation in the early days and identified that poor memory may influence their perceptions of communication in ICU. Other potential barriers to effective communication in ICU include physical barriers to verbal communication such as ET tubes and tracheostomies, patient sedation, reduced mobility due to muscular weakness, fatigue and technological interventions, the noisy environment and the presence of delirium or neurological deficits (Happ *et al.* 2011). Assessing the optimum and appropriate time to give detailed explanations to patients in ICU is fraught with difficulty and is an issue that has not received much research attention. Nevertheless effective communication and information giving was clearly valued by participants in this study and its importance emphasized in studies by Schou and Egerod (2008) and Hofhuis *et al.* (2008) whose findings indicated that patients found good communication in ICU therapeutic, reassuring better able to cope with stress.

In contrast to the reports of impersonal care many participants simultaneously spoke very highly of the care they received and how attentive nurses were to their individual needs. Even invasive technological interventions, such as performing endotracheal suctioning, were described by participants as being tailored to their individual needs. These opposing perspectives may represent the temporal element to participants' experiences: at the time they felt lonely, isolated and invisible whereas 'now', after reflection and perhaps influenced by gratitude that

they have survived, participants recount episodes of individual personal care which they see as positive. Participants appeared to transform their perceptions of their experiences over time, often re-interpreting negative experiences as positive ones. Again a tension or paradox exists. Although not highlighted by the author, this tension was evident in a study conducted by McKinley *et al.* (2002); participants reported that care in ICU was depersonalised and sometimes impersonal yet also recalled episodes of personal care where patients were comforted by the nurses presence. The transformation of patients' experiences over time was demonstrated in a longitudinal qualitative investigation of patient satisfaction with surgery conducted by Edwards *et al.* (2004). Results of this study revealed that patients, over time, transform their story, even negative healthcare experiences, into a positive encounter. Edwards *et al.* (2004) postulated that this transformation is due to the dominance of the healthcare system, the patient wanting to maintain constructive relationships with individuals providing their care and individual patients wish to maintain a positive outlook.

A lack of agency

A key thread that has permeated every theme and is at the heart of patients' experiences of technology in ICU is the inability of the patients to make and enact choice. This lack of agency is seemingly attributable to a lack of opportunity, and physical and psychosocial incapacity. Participants described how they lacked control and agency both over their physical body, their emotions, and their behaviours. Participants described how technological interventions were forced upon them where they were not active players in their care. They also described how once in place participants surrendered their agency to both technology and those managing technology- the carers.

A participant's lack of agency continues beyond simply not having a choice but actually extends to being forced to act in a certain way; participants described how they were slaves to their environment and technologies applied, others described how they had to bow down to the authority of care-givers. The domination and subjugation experienced by the participants extended into their hallucinations and delusions which frequently portrayed persecution, slavery, imprisonment. Participants described and demonstrated how they behaved like captives- following orders without question, trying to 'be good' in order to win acceptance and approval. Participants demonstrated both fear and admiration for the health care professionals by offering high praise even when at times they had felt ill treated.

Feelings of powerlessness, relinquishing one's agency and feelings of absolute dependence described by participants in this study have also been reported in the research literature. Johansson and Fjellman-Wiklund (2005) describe the experiences of patients who are undergoing mechanical ventilation in ICU as having 'limited possibilities to act'. Adamson *et al.* (2004) and Magarey and McCutcheon (2005) also suggest patients feel powerless, having a lack of control- feelings that according to Magarey & McCutcheon are exacerbated by the presence of technology and staff. Some authors (Magaray and McCutcheon 2005; Almerud *et al.* 2008) suggest that powerlessness and a lack of communication may exacerbate feelings of isolation and loneliness which was a sentiment widely expressed by the participants of this study.

When referring to technological interventions, participants of this study described how they relinquished their agency by 'giving in to it' and 'bowing to authority'. Participants went on to describe how relinquishing one's agency led to a total and forced dependence on both the technologies and the care givers. Participants inferred that at times they received care passively.

Other authors have identified that patients in ICU, particularly those receiving mechanical ventilation, were unable to engage in activities of daily life and therefore lose their independence in the simplest and most intimate matters (Holland *et al.* 1999; Almerud *et al.* 2007; Wang *et al.* 2008). Participants within this study demonstrated that the lack of agency and resulting dependency on technology and caregivers is upsetting and described feelings of helplessness, vulnerability and anxiety. Conversely, despite feeling powerless and bowing to the authority of the care givers, participants in this study expressed that they trusted both the expertise and judgement of the healthcare professionals and the technologies applied. Participants described how during this time of chaos and uncertainty how they were reassured by directions of the health care professionals. Similarly, other studies reveal that patients recognise, respect and are reassured by the competence of their carers (Rier 2000; Hofhuis *et al.* 2008; Wahlin *et al.* 2009).

Participants described how technology in conjunction with their Useless Body impaired their ability to do things such that they felt a loss of control over their body and bodily processes. Participant 12 described the frustration of not being in control of their breathing. Arguably, even in health one would not have complete control over one's body and all its processes. As Marcum (2004) identifies although the body is one's own, there is a sense in which it is independent as the body is not always controllable. Sartre (1956) however, clarifies that whilst the body involves biological processes beyond a person's control, these processes still belong to the person, as lived by the person (Svenaesus 2000a). However, during critical illness these biological processes are often externalised and depend on technology to occur. For example, during health one does not have conscious control over kidney function, however, the process still belongs to you. During critical illness, when kidney function might be impaired a haemodialysis machine

takes over the function of the kidney- the process is therefore externalised, handed over to technology. Similarly, as with participant 12, the function of the lungs was handed over to the external mechanical ventilator. Patients do not therefore just lose control of their body; there is also a loss of ownership or mine-ness.

Technological routine and being good

As well as losing agency of their own self and body, participants described a sense of helplessness to their external environment. In particular, participants described how they unquestioningly adopted and adapted to the routine dictated by the presence and application of technology. For example participant 10 was not allowed to practice walking independently due to the presence of drips and drains. These episodes are perhaps examples of the occasional impersonal nature of care in ICU. This finding reflects the nurses' perspectives of technology and care reported in studies such as Wikström *et al.* (2007) which suggested that care in ICU may be technologically focussed and highly routine.

Despite many participants expressing frustration at being restricted by the technological routine participants did not appear to challenge the caregivers. As previously highlighted, participants described how they implicitly trusted both the technologies and the caregivers without demur. The unquestioned compliance with the technological routine may also be related to the hope of survival and recovery that technology promises. Participants often rationalised the presence of various technologies in terms of the potential physical recovery it would bring- many participants reflected that they 'would have died without it'. Although studying patients having cardiac surgery, Lapum *et al.* (2010) suggested that patients succumb to the dictated technological routine as it represents a 'technological fix'. According to this study, for patients in

ICU, technologies also appear to represent an expectation of recovery. Lapum *et al.* (2010) further suggest that patients become passive to the 'fix' because they have no expertise with the technology. Patients are therefore in a position where they can do nothing but trust the technologies and the caregivers applying them.

Another factor that appeared to influence participants' compliance with and endurance of technologies is their perceived recovery trajectory. Participants in this study often staged their recovery or judged their condition according to the presence or absence of various technologies. The removal of technologies such as mechanical ventilation and tracheostomies, in particular, represented meaningful milestones in the participants' recovery journey. This finding has not been demonstrated in previous studies although Lapum *et al.* (2010) suggest that technological pathways of recovery may provide a sense of security and reassurance.

Recognising the life-saving potential of technologies, participants appeared to endure technologies as a necessary evil. Participants recognised that the acquired benefits and comfort incurred by the application of technologies such as endotracheal suction often outweighed the discomfort and encumbrance. The acceptance of short-term discomfort related to technical interventions that potentially offer long-term survival and recovery from a critical illness has been reported in the research literature (Wang *et al.* 2008; Foster 2010; Lapum *et al.* 2010). Eastwood *et al.* (2009) suggests that patients tolerate interventions if the therapeutic benefit is obvious. Even what are perceived to be invasive and distressing technologies such as mechanical ventilation are reported as providing comfort and security to patients in ICU (Johnson 2004; Schou and Egerod 2008; Wang *et al.* 2008).

Compliance with the technological routine may also be due to the patients' desire to 'be good' and please their care givers. Participants expressed how they complied with technologies for fear of being a burden to both their family and the care givers. Participants often went to great lengths not to disturb the nurses, for example participant 19 who tried to lie perfectly still so as not to make the arterial line alarm. Participants also inferred that they aimed to win acceptance from their caregivers by complying with their demands and the demands of the applied technologies. Arguably such patient behaviours are reminiscent of Talcott Parsons (1951) theory of the 'sick role' a component of which suggests that the sick person must seek competent technical help and cooperate with the caregiver. Lack of cooperation with the caregiver is seen as deviant behaviour (Friedman and Silver 2007). The medical sociologist Stockwell (1972) also described the characteristics of what is typically perceived as being a good patient: a patient who readily cooperates with their treatment, willingly conforms to the rules and does not disrupt the routine (Clarke 2010).

Within the data the lack of agency seemed to be along a continuum where control was gradually reclaimed along the recovery trajectory. Participants described how they gradually attempted, sometimes furtively, to regain control of themselves and their environment. Although participants described how they were passive in their care, participants also described how they attempted to surreptitiously influence the care they received in an attempt to regain control. For example participant 12 deliberately did not cough so that they did not have to endure tracheal suctioning whilst participant 18 deliberately slumped in the chair so that they would be returned to bed. Furtive attempts at influencing their care have not been explicitly reported in the literature however, McKinny and Deeny's (2002) study revealed that patients had a desire to regain independence. In addition, Johnson (2004) in her qualitative study examining nine

patients experiences of long-term mechanical ventilation suggested that ICU patients whilst initially were frightened and powerless, patients attempted to reclaim some level of control over their world. Johnson (2004) suggests that a patients desire to take control often signifies the beginning of their recovery. Efforts to regain control described by Johnsons (2004) participants include re-engagement with staff and families, seeking control over treatments, attempting communication and re-claiming self. Attempts to regain control may also signify the capacity for the patient to take a more participative role in their care.

Thus far, a lack of agency and compliance with the technological routine has been presented as a negative aspect of patients' experiences. The lack of patient agency appears to be at ideological odds with the key values of modern healthcare which endorses patient centred care. A key policy area in the recent Health and Social Care bill is dedicated to a greater voice for patients. In fact the government aims for there to be 'no decision about me, without me' for patients and their own care (Department of Health 2011b, Page 1). Arguably a lack of patients' agency in ICU contradicts these key values. The lack of agency and feelings of invasion may reflect the critical theorist perspective of the powerful and subjugating potential of technology. However, patients didn't describe technology as being something from which they required emancipation. Participants recognised the positive benefits of surrendering their agency during critical illness. Participants described how they felt reassured and comforted by technology. Others marvelled at the sophisticated nature of the technologies and described how technologies represent a hope of recovery. Participants also acknowledged that at the time of their critical illness they were happy not to take responsibility for the decision-making and bow to the expertise of their carers. Many participants also acknowledged that there was really no

alternative but to surrender ones agency acknowledging that often it was a matter of life or death.

Similar sentiments are reported in the wider literature. Participants in Wåhlin *et al.*'s (2009) study which investigated patient experiences of empowerment in ICU, reported accepting treatments without reflection as they regarded themselves as being incapable of being involved in decisions about medical care due to exhaustion and lack of knowledge. Lapum *et al* (2010) also suggest that relinquishing control and depending on the perceived expertise of health care professionals and the wonder of modern technology maintain a sense of security, comfort and hope of recovery. In contrast there is much evidence to suggest that patients value knowing what is happening to them and feel it is important to have a choice in their care (Russell 1999; Hupcey and Zimmerman 2000b; Hofhuis *et al.* 2008) and be included in their care. These differing views may represent the different stages of recovery where only when the most critical phase of their illness has passed would the patient feel well enough to actively participate in their care. Once again the dilemma and challenge of assessing the appropriate time in the individual patient illness- recovery trajectory to communicate and engage patients with their care is demonstrated.

Participants' accounts of technology and care represent a series of paradoxical relationships. On one hand participants perceive technology and care as inseparable, yet on the other participants clearly distinguished between technological interventions and personal nursing care. Participants describe times of impersonal care which made them feel invisible and alienated. They also described invisible or faceless care. Conversely participants also expressed immense gratitude to those that cared for them describing health care practitioners as wonderful and

attentive to their needs. In describing technologies a further paradox was evident where participants simultaneously described them as uncomfortable yet comforting, alienating yet reassuring, disabling yet enabling. Participants viewed technologies as a necessary evil where the potential life saving benefits was reconciled with the personal discomfort and encumbrance. Whilst the individual sentiments expressed by participants have been reported elsewhere in the literature the unique finding from this study is the revelation of the paradoxical relationships between these emotions and experiences. Patients appear to experience emotions across a broad range of spectra. This demonstrates the complex nature of patients' experiences and emotions and indicates the extensive skill set required by the professionals caring for them. Since the participants' experiences of technology has not specifically been reported in previous research literature, these findings offer a unique view or patients experiences of being cared for in technological environment such as ICU.

Contribution to Theory

Findings from this study resonate with existing theories of the phenomenology of the ill body however also make a clear and unique contribution to the theory base. Key phenomenological authors such as Merleau-Ponty (1962), Van Manen (1998) Sartre (1956) and Svenaeus (2000a; 2000b) provide a model of the body both in health and illness. Merleau-Ponty (1962) describes how illness is experienced in terms of the body's dysfunction. The body's dysfunction is experienced by the ill person as encumbered (Van Manen 1998) where the body no longer exists in the silent background. As such the ill person has a complex and altered relationship with their own body and ultimately Being-In-The-World. During illness, people experience their bodies as alienated and objectified yet simultaneously are inextricably theirs. Sartre and Zaner describe this as the body being not mine yet mine (Sartre 1956; Zaner 1981). This transformed state of

Being-in-the-world is described as Un-homelike (Svenaesus 2000a; Svenaesus 2000b). As described above, these key concepts outlined within the existing evidence base resonate with the experiences of the participants of this study. However, upon analysis of the data, these existing theories do not comprehensively explain the totality of the experiences of the patients' *critically* ill body. Phenomenological authors have previously grounded their suggestions on the experiences of less acute, chronic illness and mental illness. Therefore existing phenomenological models of the ill body do not exhaustively explain the experiences of the centrality of the body in pain, and the disintegrated and invaded critically ill body in an intensely technological environment where there exists the intense fear of death and disability. This study makes a clear and unique contribution to theory as it builds on the phenomenology of the ill body and highlights the unique features of the critically ill body in a technological intense environment.

This study revealed for the first time the critically ill body becomes central to the patients understanding of their experiences. The body is not just experienced as dysfunctional and encumbered but the dysfunction and pain is so great that the critically ill body dominates being-in-the-world to the extent that all other understandings are eclipsed. Further than being Un-homelike as suggested by Svenaesus (2000a; 2000b), the critically ill person experiences their body as disintegrated and invaded both by technology and the critical illness itself. So dominant is the patients experiences of their 'Useless Body' that all other understandings of ICU and the technology encountered are embedded within that context. Therefore, Technology and Care and Making Sense of It whilst presented as discrete themes are underpinned and enmeshed within the patients perceptions of their disintegrated, invaded, 'Useless body'.

Figure 6 provides a conceptual framework of the Phenomenology of the Ill Body incorporating the novel concepts of the Phenomenology of the Critically Ill Body and demonstrating how all other understandings of ICU such as 'Technology and Care' and 'Making Sense of It' are founded on their experiences of 'My Useless Body'.

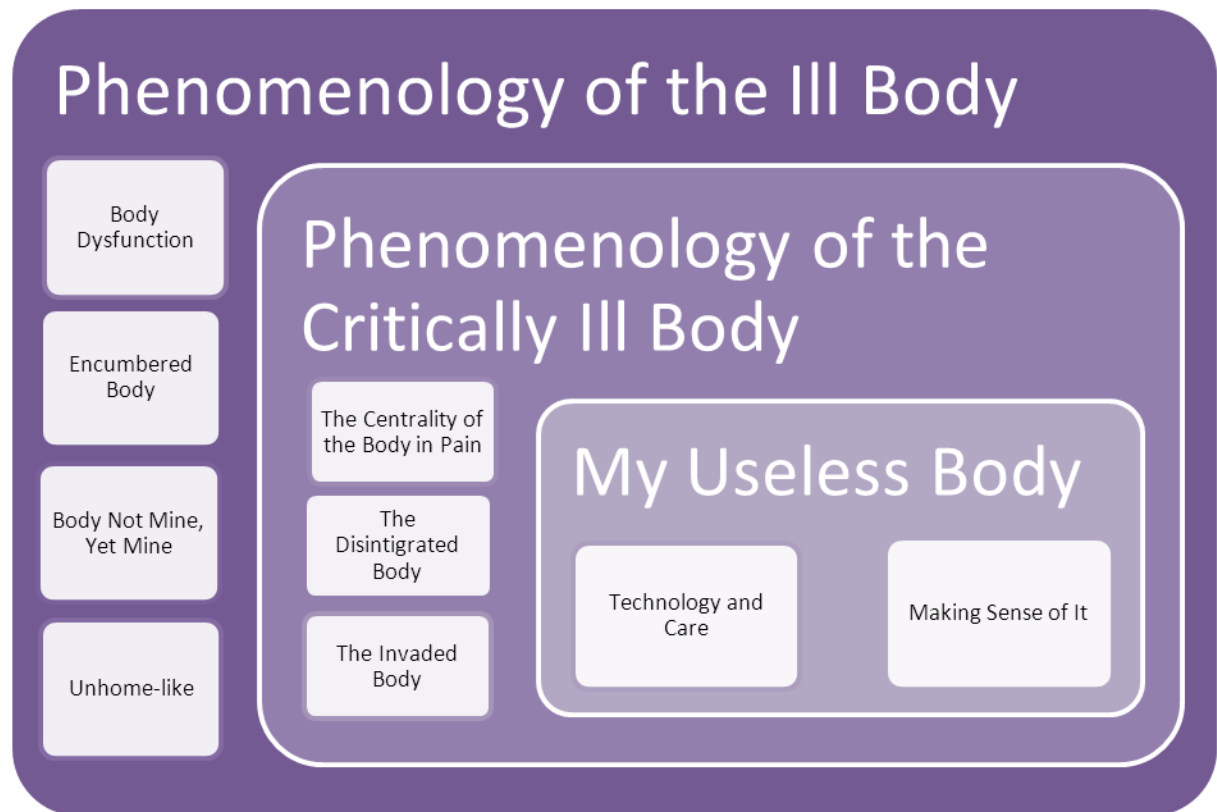


Figure 6: Conceptual Framework: Contribution to Theory

Discussion of Methods

The following section discusses the methods employed in this research study highlighting the challenges faced whilst conducting this research, and the limitations and scope of the research. As previously identified, a Heideggerian phenomenological approach to research is concerned with individual experiences of a phenomenon and characteristically generates rich accounts that

are intertwined with the cultural, historical and social context (Mackey 2005). As such, participants' accounts of technology within ICU were a fusion of their overall experiences of having a critical illness and being in ICU and specific experiences of technology. Whilst being a challenge to tease out specific understandings of technology in ICU this is inherent with Heidegger's notion of being-in-the-world. Given the lack of previous research into patients' experiences of technology in ICU, a Heideggerian approach has allowed a broad exploration of phenomenon providing a rich understanding of patients' experiences of being cared for in a technological environment. The following section provides a reflection on the process of conducting the research utilising the methods chosen in relation to the expressions of rigour (balanced integration, openness, concreteness, and resonance) suggested by De Witt and Ploeg (2006). In addition, limitations or areas of potential improvement are highlighted.

Recruitment

The initial aim was to recruit between thirty and thirty-five participants from the population of patients who had been cared for in ICU for more than four days, however in the actual study, only nineteen participants were recruited. This was more than adequate to ensure data saturation; no new themes emerged after 15 interviews, the final four serving to enrich and consolidate the existing themes. Recruitment was a challenge as it took over eighteen months to recruit the sample. The exact number of invitations sent to prospective participants was not formally recorded however a conservative estimate would be approximately 150 letters. My study design only recruited patients who agreed to attend follow-up clinic which automatically restricted the population available. In addition some follow-up clinics were cancelled at the last minute due to staffing difficulties. Other than the 19 participants who did take part, most invitees just did not respond, however several patients telephoned to state categorically that

they neither wished to attend follow-up clinic nor participate in the research. These callers were quite impassioned about their refusal to participate some stating that their experiences in ICU were so awful that they did not want to re-visit them. Others stated that they wished to put their traumatic experiences behind them and move on with their lives. The psychosocial impact of critical illness has been explored within the reviewed literature of this study and has been further revealed in the participants' accounts. The reluctance of some patients who have survived critical illness is therefore understandable. In particular, patients who felt they could not clearly remember their experiences may have been deterred from participation. Difficulties in recruiting ICU patients have been reported in other similar studies with reasons such as short length of stay, high mortality and impaired cognition being cited (Gustad *et al.* 2008).

Other potential reasons for the difficulty in recruiting patients in this study are more pragmatic. During the data collection period there was a prolonged postal strike which may have led to the delay in patients receiving their invitations or even the mislaying of some invites. Furthermore the period incorporated a period of heavy snow fall which made road travel difficult with limited public transport options. Given that the hospital studied serves a large rural community, many participants may have been discouraged by the difficult travelling conditions. Potentially recruitment may have been improved if I had offered to interview patients in their own home.

The strategy to recruit patients a minimum of 3 months after ICU discharge whilst attending their follow-up clinic appointment was largely influenced by pragmatic reasons which led to a number of limitations in recruitment, the subsequent sample and ultimately the data generated.

The eventual sample only represents a very small, self-selected subset of the whole ICU population. The strategy precluded patients who were not eligible to attend follow-up clinic such as those who had stayed in ICU less than four days and those patients who had been discharged from ICU but were still an inpatient in hospital. It also precluded patients who had been discharged from ICU but did not survive three months after discharge. In addition there were potentially patients who may not have wanted to attend follow-up clinic but may have been interested in participating in the research- these too were inadvertently excluded.

The chosen strategy relied on patients actively remembering or having the confidence to express their interest in participating in the research to the critical care outreach secretary when she telephoned to confirm their follow-up clinic appointment or having to take the initiative and contact me directly. Whilst the critical care outreach secretary aimed to remind the patients of the invitation to participate in the research, this process was inconsistent in its execution. It was apparent that many more patients attended follow-up clinic than volunteered to participate- there is no way of knowing if all of these actively did not want to participate in the research or if some simply had forgotten to or lacked confidence in actively volunteering.

As a result of the limited sample, the data generated may have a limited richness and diversity. Subsequent recommendations may therefore not be transferable to all ICU patients in all ICU settings. However given that the findings from this study clearly resonate with the existing evidence base the trustworthiness of the data is inferred. Whilst the recommendations may not be directly applicable to all ICU patients in all ICU settings, their strengths lie in offering tentative concepts that would benefit from further research.

There are a number of measures which may have resulted in a more effective recruitment strategy and might be considered for future similar studies. Patients who are well enough and have adequate mental capacity could be recruited whilst still on ICU or soon after their discharge whilst an inpatient on the ward. Patients who have been discharged home could be interviewed within their own homes rather than relying on their attendance at follow-up clinic. In addition, follow-up clinic staff could ask attendees if they are willing to meet the researcher. The researcher could then explain the study, address concerns and answer queries face to face. The participant information sheet could state more explicitly that patchy, unclear memories are normal in patients who have been in ICU and that a complete and clear memory is not a pre-requisite to participate. The information sheet could emphasize that any patient contribution to the understanding of the phenomenon is valuable. The critical care outreach secretary could have a clearer directive to specifically ask patients if they are happy to be contacted by the researcher during the follow up clinic appointment confirmation telephone call.

A more effective recruitment strategy may have generated a wider diversity of the ICU population potentially resulting in a richer account of experiences of technology in ICU. This in turn would have led to more robust theme development and a greater transferability of the findings leading to greater trustworthiness of the recommendations.

Sample

Amongst the 19 participants there was a range of ages, diagnoses and lengths of stays. Although not formerly measured or recorded it was evident from participant accounts that there was a range of illness severity amongst the sample. The level of diversity within the sample is reflective of the general ICU population. This study was a single centre study where the sample

consisted of only white English- there was no ethnic diversity within the sample. An international or even a multi-site study would have increased the diversity of the study population. It is acknowledged that transferability of the findings from this study may be limited as other settings may have differences in their organisation, and study populations may have more diverse ethnic, cultural, and socioeconomic backgrounds. However, the discussions of the findings demonstrate how the study population's experiences resonate with other published research therefore indicating confirmability and transferability of the findings.

Most participants attended follow-up clinic, where they were interviewed, three to four months after discharge from ICU, however, due to organisational factors, some participants had been discharged from ICU up to seven months earlier. The retrospective nature of this study therefore relied on participants' recollections of their lived experience sometime after the event. The accuracy of recall may have been distorted to varying degrees over time. Conceivably participants who were interviewed later in their recovery trajectory may have re-formulated their understandings differently over time compared to those who were interviewed earlier in the process. This may have led to some variation in the accounts. In addition, participants' perceptions might be influenced by the fact they were not yet fully physically and psychologically recovered. In particular, participants reported having fragmented memories of their stay in ICU which may limit the authenticity of some of their accounts of their experiences as they may constitute of a mixture of their own factual memories, unreal memories and information subsequently given to them by family members or healthcare professionals. Arguably, however, the fragmented, unreal memories, and piecing together of information is so ubiquitous to being in ICU that it is in itself the authentic experience providing a valuable and credible insight into the process of making sense of the ICU experience.

Data Collection

The interviews were carried out in a private office in a hospital setting before or after the follow-up clinic appointment. Heideggerian phenomenology emphasises the importance of situatedness of experiences (Delmar 2006). Conducting the interviews within the context in which their experiences occurred, in this case ICU, may be regarded as a marker of rigour. However, due to pragmatic and ethical consideration interviews were unable to be conducted in ICU at the time of their illness but were conducted in the outpatients department of the hospital. A potential limitation of conducting the interview in the formal environment of a hospital outpatient clinic is that patients may feel inhibited in giving honest and authentic accounts. Despite emphasizing that I was not an employee of the hospital and that their participation within the research would have no influence over their subsequent care, participants may have felt reluctant to divulge negative experiences or experiences that were critical of their carers or the organisation. Therefore whilst every effort was made to ensure authenticity of participant responses, there is always a danger that participants only describe what they perceive to be socially acceptable experiences and withhold details of some experiences that they perceive to be socially undesirable. Again this potential limitation may have been overcome had the patients been interviewed in their own home.

Upon their request, some participant's spouses were present for the interview. Arguably, the presence of a relative who would have their own experiences of the ICU, may have influenced the participants accounts of their experiences. However, I was careful to explain to the participants and their spouse that the research aimed to investigate the patients' experiences and not those of the relatives. Mostly when spouses were present they sat quietly and only interjected to clarify factual bits of information such as dates of events, length of times. I felt

that the presence of relatives actually reassured the participants and enabled them to relax sufficiently in order to give a detailed account of their experiences. At no time did I feel that the presence of the relatives in anyway negatively influenced or impeded the interview process.

In order to facilitate the development of an 'engaging conversation' style of interview required for a Heideggerian style interview (Finch 2004; Lowse and Prowse 2001), prior to commencing the interview I spent a little time generally conversing and having refreshment such as a cup of tea with the participant. This informal social engagement not only gave the participant ample opportunity to ask questions about the research but also allowed us to get to know one another. As a result, all participants appeared to be at ease at the commencement of the interview.

Again as a means of promoting a conversational style of interview I allowed participants to speak freely with only minimal prompting at convenient junctures. Participants therefore directed the course of the interview. On occasions, some participants wandered off topic and discussed issues not directly relevant to the research. I attempted to use prompts from the interview topic guide to re-direct the participant accounts of their experiences. I found this difficult as often participants were describing aspects of their ongoing recovery which, whilst not directly relating to the research aim, as a critical care nurse and academic was very interesting. As a result some interviews were very lengthy and I found active listening over such a sustained period a challenge. Conversely, the detailed descriptions of the participants' experiences helped to contextualise their accounts and I believe allowing the participants to explain their experiences in their own words and in their own time ensured authenticity of their accounts. The contextual information and authenticity of accounts may add to the concreteness of the

research as the findings are orientated within the broader social context (De Witt and Ploeg 2006).

A repetitive theme within my reflexive diary entries after participant interviews was the tension I felt between being a professional nurse and a researcher. When describing distressing experiences or ongoing anxieties, instinctively as a professional nurse, I wanted to counsel and advise patients; however, I had to be constantly mindful that such activities would be outside of my remit as a researcher. Arguably, in an engaging two way conversation deemed essential for a Heideggerian approach it is feasible that a reasonable response to an expression of distress or anxiety would be words of reassurance and advice- anything else would seem unnatural and may serve to stilt the natural flow of conversation. As such, where appropriate I reassured participants and at the end of the interview encouraged participants to share their ongoing concerns with staff in the follow-up clinic or their GP.

Data analysis

As discussed in the research methods chapter findings and themes were not member checked which might be viewed as a limitation by some. However, since theme development was emergent I was able to review my interpretations and reflect them back to the participants during the interview process. In addition, theme development was discussed with my PhD supervisors and constantly cross referenced to the raw data and my reflexive diary. The reflexive diary and general field notes detail the decision making process in theme development. The annotated transcripts and draft conceptual maps represent an audit trail of the evolution of the themes. Such measures demonstrate openness of the research process which De Witt and Ploeg (2006) highlight as an essential expression of rigour in Heideggerian phenomenological studies.

In presenting the findings I have illustrated the themes with participant quotations to substantiate the derived themes. Balanced integration where there is an appropriate balance between the participants' voice and philosophical and theoretical explanation is again an expression of rigour (De Witt and Ploeg 2006). Balanced integration also incorporates assimilation of the methodology throughout the research process. I have therefore looked to Heideggerian philosophy to inform not only the research methods but also the data analysis and discussions. In addition, as detailed in the discussion, derived themes resonate with existing literature which indicates confirmability and potential transferability of the study findings.

A Heideggerian phenomenological approach acknowledges the inseparability of the researcher from the researched. As a critical care nurse and academic I reflected on my past experiences of caring for patients in ICU. Entries made in my reflexive diary prior to conducting the research identifies that I preconceived technology to be essential but potentially unfamiliar, frightening and stressful for the patient. From my clinical experience I have witnessed firsthand the technological interventions such as tracheal suctioning that patients find distressing. I also acknowledged that technology is so engrained in my own critical care practice I had a complacency towards technologies particularly those that are not specific to ICU such as venepuncture, pulse oximetry and intravenous infusions. I appreciate that I could not have bracketed out these preconceptions and experiences even if I wanted to adopt a Husserlian approach as I fear that I would have inadvertently influenced the data anyway. My experiences enriched the data as I found that my understanding of the ICU environment facilitated the interview process. Notes made in my reflexive diary highlighted that my clinical experience enabled me to empathise with the participant, thus encouraging open and honest dialogue and

generating a potentially richer account of their experiences. Comparison of reflexive diary entries made prior to data collection and those made immediately after interviewing each participant were useful in explicating my own influence over the interpretations of the participant data. This allowed for further openness and transparency of theme development. In addition, I was able to utilise my reflexive notes to reflect on my interpretations which I could then discuss with other participants in subsequent interviews. These measures served to ensure openness as well as maintain a balanced integration of participant and researcher voice within the co-construction and interpretation process.

In this study, a Heideggerian approach was pivotal in ensuring that the ICU patient's voice was heard. Heideggerian phenomenology is patient centred and offers a forum for patients to tell their story in their own words and describe experiences that are meaningful and significant to them. This approach enabled explication of both what was experienced in ICU but also how it was experienced. The individual and personal contextual information provided richness to the participants accounts which all relates to the quality of the patients experience which is high on the health care agenda (DoH 2011a). However, context specificity may also be a limitation as findings specific to the given context may not be easily transferable to other settings. Another limitation is that interviews may be lengthy and generate large amounts of transcript data. Data management and subsequent analysis then becomes a challenge.

Summary

Attempts were made to adhere to the expressions of rigour suggested by De Witt and Ploeg (2006). The limitations of the study, such as slow recruitment process, a sample that lacked cultural diversity, were largely due to pragmatic reasons rather than methodological oversights.

Adopting a Heideggerian phenomenological approach in retrospect was the best approach to fulfil the research intentions, although it is acknowledged that by its very nature the transferability of findings to other contexts may be limited.

Chapter 7: Conclusions and Recommendations

NICE (2009) approximate that 110 000 people in the UK spend time in critical care areas with the majority surviving to be discharged home. Recent research has highlighted that a significant number of patients surviving critical illness have continuing physical and psychosocial problems long after discharge from hospital (Adamson and Elliot 2005; Ringdal *et al.* 2009; Griffiths and Jones 2011; Morandi and Jackson 2011; Samuelson 2011; Stransky *et al.* 2011). The impact of critical illness and the associated long-term health issues not only affects the patient but may also have a ripple effect on families who become informal care givers which in itself may exert a secondary toll of ill health. Insufficient rehabilitation from critical illness therefore represents a major public health issue (NICE 2009). In recent years there has been a change in focus in both clinical care and research attention where optimisation of recovery as a therapeutic objective is prioritised rather than just merely surviving the ordeal (NICE 2009).

In a bid to enhance understanding of the patient's journey through critical illness, and clarify the nature of stressors encountered during critical illness this study has examined the complexities and multi-dimensional experiences of patients' who are cared for in the technological environment of ICU. Phenomenological research offers the opportunity for us to understand the experiences of others. Technology is fundamental to treating and caring for the critically ill patient in ICU. The research findings can facilitate healthcare professionals' awareness of patients' perceptions of being cared for in a technological environment and the responsibilities that healthcare professionals have in influencing the care and the experiences of patients in ICU and beyond. Within this final chapter, the unique contribution of this study is described and

discussed. Implications and recommendations arising from this study's findings on nursing practice, education and future research are suggested.

The findings of this study provides several new dimensions to the knowledge and understanding of both the patients general experience of ICU and the specific experiences of technology and being cared for in a technological environment. A summary of the unique contributions of this study to the evidence and knowledge base is summarised in table 2.

Table 2: Summary of Unique Contributions

Theme	Unique Contribution
My Useless Body	<ul style="list-style-type: none"> • The body is central to the critically ill persons experiences in ICU • Critical illness is experienced as the resulting dysfunction of the critically ill body • The body is experienced as mine yet not mine • The body is disintegrated and invaded which dominates the patients' being-in-the-world • Patients experience emotions and behaviours that are uncharacteristic and unfamiliar to them • A preliminary phenomenological model of the critically ill body is suggested
Making Sense of It	<ul style="list-style-type: none"> • Participants attempt to construct a meaningful and understandable story which is temporally cohesive early on in the recovery process • Participants factual memories are mainly of events such as family visits, procedures and interventions and not of their surrounding or staff caring for them • The surrounding technologies are often incorporated into the patients delusions and hallucinations • It is important to the participants to attempt to sort real and unreal memories • In order to sort the real from the unreal memories, participants gather information, predominantly from their family, to fill in the gaps and rationalise their memories
Technology and Care	<ul style="list-style-type: none"> • Participants experience technology and care as an inseparable, unified experience. This aligns with a social constructivist philosophical perspective • Experiences of technology and care are a series of paradoxical relationships: impersonal yet personal, invisible yet well cared for, alienating yet reassuring, disabling yet enabling, uncomfortable yet comfortable • Participants have an existential view of care valuing the personal and humane elements of care • Participants experience invisible and faceless care • Both the nurse and patient in ICU may be enframed by technology • Participants gauge their condition by the absence or presence of technologies • Participants attempt, often furtively, to regain agency

My Useless Body

The findings of this study emphasise that the critically ill body is central to the experience of patients in ICU. Participants' accounts identify immense suffering where they feel disconnected from their disintegrated and invaded body experiencing their body as mine yet not mine. Participants' experiences contribute to a phenomenological understanding of the critically ill body which also begins to explain the bodies' relationship with technology in ICU. This insight offers a novel perspective since existing phenomenological considerations of the ill body have been chiefly concerned with less acute, chronic and mental illnesses (Van Manen 1998; Svenaeus 2000a; Fredriksen *et al.* 2008; De Preester 2011). The phenomenological understanding of the critically ill body reveals that the body in pain is central to the patients' experiences to the extent that it presides over all other understandings of being-in-the-world. The patients' being-in-the-world is brutally disrupted. The critically ill body is understood not in terms of its biomedical insufficiencies but in terms of its dysfunction. Furthermore the critically ill body becomes objectified into disintegrated body parts whilst retaining a sense of mine-ness as revealed by the sense of invasion by technologies.

The Heideggerian view that human understanding is a construction which is inseparable from the social, historical and emotional context suggests that patients experiences and constructions of understandings may be transformed depending upon the social, historical and emotional context. This premise places health care professionals at the heart of the patient's experiences since they are present within and may influence the critical care context. In addition phenomenological understanding of the patients critically ill body is significant to health professionals caring for the critically ill patient at all stages of their illness and recovery as it may

re-focus the carers attention and appreciate critical illness from the perspective of the patient rather than understanding critical illness in biomedical terms.

The phenomenological model of the critically ill body recognizes the fundamental disruption to a patient's being-in-the-world thus highlighting the need for healthcare systems to not only address the diseased body parts but to also help patients cope with their altered state of being-in-the-world. This study revealed that the critically ill patient with a disintegrated, invaded body is associated with high levels of anxiety and suffering which may further contribute to the disruption of their being-in-the world. The enormous amount of physical and psychological stress is a continual challenge for intensive care nursing and medicine. This finding alone strongly suggests that critical care follow-up clinics and the on-going psychosocial care after discharge from ICU could be significant to patients' long-term recovery. However, as well as dealing with the aftermath of critical illness, healthcare professionals in ICU may seek to minimise or alleviate the stress, fear and anxiety encountered during the patients' ICU stay. Arguably, the disintegrated body is inevitable during critical illness; as are the technologies required to treat it. Therefore the imperative is to reduce the impact of the stressors associated with an ICU admission and critical illness. Access to patients' experiences of the disintegrated and invaded body gained by phenomenological consideration may sensitise healthcare professionals to the gravity and traumatic nature of patients' experiences allowing them to respond compassionately and empathetically to the suffering associated with critical illness. Health care professionals, nurses in particular, are ideally placed to recognise anxiety and suffering and furthermore implement measures to reduce and alleviate stress incurred. Nurses may also be in a position to offset the objectification of the body and illness that is exacerbated by technologies and focus physiological measurements and enter a caring framework that

places the patient at the centre of their care. The significance of this role is highlighted by Marcum (2004) who suggests that by relieving the patients' anxiety and suffering, the home-likeness state of being an embodied person in a unique life-world may be re-established so that the patient heals even though the disease may still prevail.

Making Sense of It

Participants demonstrated the importance of constructing a meaningful and understandable story of their critical illness and ICU admission. Some participants even commented that the process of the research interview was beneficial in helping them to understand what had happened to them during their ICU stay. Participants demonstrated that a temporally and causally coherence is essential in the construction of their stories. Telling a story leads to understanding which according to Heidegger is developed as a primary concept of attaining meaningfulness (Williams 2009). Finding meaning in their ICU experiences may be of decisive significance to the patient in regards to their psychological recovery. The significance of this finding is demonstrated with consideration of Storli *et al.* (2008) who interviewed patients ten years after their critical illness and described how they continued to attempt to make sense of their experiences in what their participants described as a journey in the quest of meaning. The patients understanding and what their critical illness means to them therefore is of significance to the patient both in the immediate recovery phase and in the long-term.

Participants' factual memories are mainly of events such as family visits, procedures and interventions. This highlights the patients' family members as key players in the patients care and ongoing recovery. This finding also demonstrates that patients in ICU may have clear memories of potentially invasive and traumatic interventions. Memories of factual events seem

to contribute to the sense making process. These experiences and memories become memories that patients carry with them and can thus be significant for future quality of life and health.

During their accounts participants also described the importance of distinguishing between real and unreal memories. These findings support previous suggestions that formulation of a complete comprehensible story is important in the psychological recovery of patients who have been in ICU. The importance of family members in the care and recovery of patients in ICU is further highlighted as participants seemed to predominantly rely upon family members to fill in the gaps and rationalise their memories. Since the presence of real factual memories are thought to offer some protection against the subsequent development of PTSD and other psychological pathologies (Jones *et al.* 2001; Griffiths and Jones 2011) highlights the importance of facilitating patients' construction of their understandable story. This finding is of significance as it may provide clarification to health care providers of the purpose of rehabilitative activities and strategies initiated both in ICU, and during follow-up.

Of particular significance is that participants appeared to process their experiences and construct a story very early on in the recovery process. This finding supports the NICE (2009) directive that rehabilitation strategies ideally should be implemented early in the patient's recovery and should not wait, as it has done previously, until physical recovery. Early support from health care professionals in understanding and finding meaning in their experiences may assist patients in both their long-term physical and psychological recovery after discharge from ICU and hospital.

Technology and Care

The data reveals that there is a paradoxical relationship between technology and care: uncomfortable yet comforting, alienating yet reassuring, disabling yet enabling. Clearly participants had both positive and negative experiences of care during their time in ICU. Positive experiences were often associated with a strong nurse presence. For example participants particularly valued personal and compassionate care such as acts of affection (hand holding), attending to personal hygiene needs (face washing, teeth cleaning). Participants described how these personal and individual acts of care were comforting and reassuring. This finding is significant as it highlights the importance of a holistic and person-centred approach to care approaches that reflect the key values at the heart of healthcare reforms outlined in the NHS White Paper, 'Equity and excellence: Liberating the NHS' (DoH 2010). It also accentuates the importance of the nurse and the role they play in not only meeting the physical care needs but also in providing comfort, reassurance and reducing patients' anxiety in ICU.

Participants also described times of loneliness, isolation, anxiety and confusion when perhaps their care needs were not being met. Participants described times when nurses were concerned with practical technological tasks such as the monitoring of ICU technologies which they described as impersonal. Arguably, it would appear that from a patient's point of view, nurses give priority to symptom management and treatment interventions. In this highly technological environment, patients' emotional and psychological needs may therefore not be prioritised and even at times neglected. Nurses are therefore faced with the challenge of attending to the technological interventions essential to patients' survival and recovery whilst meeting the patients psychological and emotional care needs. This demonstrates the schism between technology and human caring that has been widely debated in the literature. One main

achievement of this study is to offer the unique perspective of the patient which again is a significant contribution to the UK healthcare agenda to place the patient at the heart of all decisions and measuring patients experiences of their care (DoH 2010; DoH 2011b).

The data indicates that there were some communication deficits. In particular participants reported that some activities were not adequately explained to them. Patients demonstrated that they did not fully understand the technologies that were applied. There is a possibility due to patients' impaired memory recall and sedation that participants forgot any explanations that were given. However, given that impaired communication is reported as being a significant source of stress in ICU patients and effective communication has been associated with improved physical and psychological outcome there is an imperative to develop more effective communication strategies between healthcare professionals and patients in ICU. Such developments are significant to the broader health care agenda as the drive for patients to become partners in their care and play an active role in decisions about their care, relies upon effective communication and information sharing between healthcare professionals and patients (DoH 2011a; DoH 2011b).

The paradoxical nature of patients' experiences of technology and care demonstrates the complexity of patients' experiences of both their critical illness and the care they receive whilst in ICU. The individual nature of patients experience is also reflected in the paradoxical experience which highlights the importance and significance of phenomenological investigation of this type. A major challenge in the management of the psychosocial ramifications of critical illness is the constant presence of technology, the traumatic nature of critical illness and the necessary prioritisation of addressing life-threatening physical problems. However, the

psychosocial ramifications of the potential stressors are amenable to management by health care professionals. Effective management relies on accurate assessment of patients' needs and the careful planning of effective interventions which in light of patients fluctuating experiences and ever changing care requirements is rife with difficulty. These findings emphasise the professional and clinical expertise health care professionals require to assess, recognise and address the complex needs of the critically ill patient throughout all stages of their illness and recovery trajectory.

Technology whilst playing a fundamental role in recovery and survival of the critically ill patient also contributes to patients' complex and variable experiences in ICU. Significantly the presence of technology appears to contribute to the stress endured by patients in ICU whilst simultaneously providing comfort, and reassurance. Technology is undoubtedly embedded within ICU therefore a deeper understanding of the patients' perspective may help health care professionals manage the consequences of technology more effectively.

Recommendations

Recommendations for practice

Within this study, participants described how they endured immense levels of physical and psychological suffering during their ICU stay. This gives rise to several implications for nursing practice and management of patient care in ICU. The following recommendations and principles based on the study findings may inform the development of holistic, family-centred care strategies in clinical practice as well as undergraduate, postgraduate education and preceptorship programmes.

1. It is important that health care professionals in ICU are fully aware of the extent and complexity of the patient's experiences in ICU in which the dysfunctional body is central. This includes not only a biomedical and technological appreciation of critical illness, but the existential and psychosocial impact, which should be emphasised in education and preceptorship programmes
2. Nurses, cognisant of the alienating potential of technology, may implement and manage technologies in a way that not only recognises their capacity to rectify physiological deficit but also recognises their potential to provide comfort, reassurance and a hope of survival to patients
3. Professionals caring for the critically ill need to be mindful of the importance of maintaining a close and supportive presence in a way that recognises and is sensitive to the lived experience of an individual patient's disintegrated and invaded body. Nurses being alongside as well as beside the patient may minimise the invasive and isolating potential of technology and make care more visible and personal
4. Nursing care measures such as providing simple personal comfort and hygiene are greatly valued by patients during their critical illness and potentially provide therapeutic benefits that extend beyond maintaining their physical needs, but actually provide emotional and psychological comfort too. This reinforces the importance of nurses in ICU balancing care interventions that makes patients actually *feel* better with managing the healthcare technologies essential for their physical recovery.
5. ICU patients where their disintegrated and invaded body dominates their being-in-the-world may benefit from being reminded of normal and more pleasurable body sensations such as therapeutic massage or touch therapy. The use of touch therapy has already been

preliminary investigated and shows promising results in terms of comfort and relaxation in the ICU (Henricson *et al.* 2009).

6. Participants described how technologies in ICU hindered communication which they described as contributing to their stress and anxiety. Augmentative aids such as alphabet or picture boards and paper and pen should therefore be considered as a means of improving communication.
7. Clear and repeated explanations of technologies, unit routine, equipment, alarms, interventions, procedures and progress from health care professionals not just at the time of ICU care delivery but during the recovery period may alleviate patients' anxiety and stress.
8. Healthcare professionals need to recognise that patients may wish to participate in their own care and be involved in decisions about their care where possible and appropriate. Suggested activities in which patients might initially be encouraged to participate include hygiene activities, patient positioning, breathing and mobility exercises and decision-making regarding visitors and rest periods. These recommendations compliment the NHS strategy of forming cohesive partnerships in care (DoH 2011a) and offers pragmatic suggestions as to how this may be reconciled in clinical practice.
9. The recognition of the important role played by families in representing a familiar and comforting presence during a patients ICU stay and the role they play in patients' long-term recovery may inform the development of family-centred care strategies. In particular families not only need to be informed of the role they play in their loved ones psychosocial recovery, they also need to be provided with the necessary support and given access to the required information resources in order to successfully fulfil this expectation.

10. Ward staff caring for patients discharged from ICU need to know the nature of the ICU patients' experiences and their psychosocial needs so that they can support them in their early psychological recovery on the wards. Ward staff may also assist patients who have any questions about their experiences by providing them with the appropriate information or make appropriate referrals to critical care outreach.

Recommendations for further research

There are several areas arising from this study that may benefit from further research:

1. This study has contributed to the development of a phenomenological model of the critically ill body. Further phenomenological research specifically investigating perceptions of the critically ill body may further clarify this suggested model.
2. This study suggested that the construction of an understandable and meaningful story is significant to patients recovering from critical illness following admission to ICU which leads to two key suggestions for further research. Firstly, interventions that might facilitate story construction such as patient diaries or nurse-facilitated de-briefing may be evaluated and compared. Secondly the extent to which the construction of a story is beneficial might be explored using a mixed method approach. A qualitative investigation may explore the patient perceived benefits of constructing their story, whilst a quantitative approach to evaluation might deduce exact outcomes such as incidence of anxiety, depression or PTSD. All of these measures have the potential to inform health care professionals of how best to support patients during their psychological recovery after critical illness and ICU admission.
3. This study highlighted that families presence and support is of significance to patients whilst in ICU and during their subsequent recovery period. Exploration of families' perspectives on

providing this supportive role would be beneficial. A deductive assessment of families' needs during this time would enable healthcare professionals to facilitate strategies of supporting family members in supporting their critically ill relative.

4. Patients described specific stressors often associated with technologies and described factors that provide comfort and reassurance. A deductive exploration which clarifies the exact stressors encountered by patients, and the factors which provide reassurance, hope and comfort to patients may assist in the development of strategies of care that serve to minimise stressors and their impact. Existing tools such as the ICU environmental stressor questionnaire (ESQ) utilised by Cornock (1998) and Pang and Suen (2008) would require significant revision to take into account changes in technologies and health service provision, cultural factors and to gain specific input from service users. The use of a questionnaire together with qualitative investigation may identify the specific stressors that patients found the most stressful and gain patient perceptions of which strategies may most effectively alleviate their stress.

Final Reflections

Within the literature ICU patients' perspectives are comparatively under represented. This may be due to the inherent difficulties in investigating this vulnerable group of patients who have been through life-threatening, physically and psychologically traumatic experiences. As a novice researcher the challenges of researching such a group were great and at times seemed insurmountable, however this study has given this not often heard group of patients a voice, making the challenges worthwhile. As an academic and a clinical practitioner I was intrigued and interested by many of the patients' stories, however, as a person, being-in-the-world, patients'

sentiments of fear, separation, loneliness and vulnerability spoke the loudest. Participant 6 and 4 express this in a way that I am unable:

'I felt just separated from it, I didn't know what was going on and the person that they were discussing the person attached to the machines wasn't me, like it was somebody else. It was like being in a world that wasn't real' **(Participant 6 lines 76-79)**

'I've never been surrounded by so many people and felt so alone, I've never had so much attention yet felt so neglected' **(Participant 4 lines 196-197)**

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Appendix 1: Participant information letter



Louise Caroline Stayt
School of Health and Social Care
Ferndale Road
Swindon
Wiltshire
SN2 1HL
Tel: **01793 437409**
lstayt@brookes.ac.uk

Patient's experiences of technology in Adult Intensive Care

Dear Sir or Madam,

My name is Louise Stayt and I am currently studying for a Doctorate in Nursing. As part of my studies I am undertaking a research project exploring patients' experiences of technology in intensive care.

I would like to invite you to participate in the above research project. Please find enclosed an information sheet describing the purposes of the research.

If you are interested in participating in the research project or would like to hear more about the study, please contact me by telephone, email or post (detailed above). Alternatively, when confirming your attendance at the follow-up clinic with Nikki Kavanagh (Follow-up clinic and outreach administrator) you may express your interest and with your consent, I will telephone you.

Yours Faithfully,

Louise Caroline Stayt

Appendix 2: Participant Information Sheet



**Participant information sheet:
Patients' experiences of technology in intensive care
Version 2**

I would like to invite you to take part in a research study that examines patient experiences of technology in the intensive care unit. It is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

I am interested in finding out more about your experiences of technology during your stay in the intensive care unit (ICU). Technology plays an important role in the clinical care of critically ill patients in ICU. Some patients who have been in ICU have reported that technologies such as the ventilator (breathing machine), drips and drains as being stressful. We would like to know more about what it is like for people who have been in ICU, what was helpful for you, what you liked and didn't like and how you coped. Understanding your experiences of technology in ICU may help staff to care for future patients.

Why have I been chosen?

You have been chosen because you have been a patient in ICU for four or more days. I am asking up to 35 patients to take part in this study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care that you receive.

What will happen to me if I take part?

If you are interested in taking part you may contact me, Louise Stayt, directly using the contact details included. Alternatively when Nikki Kavanagh (outreach and follow-up clinic administrator) telephones you to confirm attendance at follow-up clinic you may express your interest and with your permission I will then telephone you. If you agree to take part, I would like to arrange, for you to chat to me about your experiences of being a patient in ICU either before or after your follow-up clinic appointment at the John Radcliffe Hospital.

Our time together would cover what it was like for you as a patient in intensive care, your experiences of technology and what part you felt technology played during your illness and recovery. It is anticipated that the interview will be up to one hour. However, if you would like to finish before this time or meet several times for a shorter duration that will be fine. If you feel tired or want to stop at any time you may do so.

With your permission the interviews will be audio tape-recorded. I may also jot down key words during the interview. I will transcribe the interview and type up what we said. You may like to have a copy of what we said.

In order to maintain your confidentiality your name will not be used. Anonymous quotations from what you said may be used to illustrate themes that arise from the data. All materials will then be stored in a secure place for 10 years and then destroyed.

Expenses

It is anticipated that the interview will take up to an hour over and above your follow-up clinic appointment. I will therefore reimburse any additional hospital car parking costs incurred as a result of taking part in the research.

What are the possible disadvantages of taking part?

I believe that the risk of any potential adverse effects of taking part in this study are minimal. If at any time during the interview you become tired or upset the interview will be stopped. You will be free to withdraw from the study at any time without giving a reason and without affecting the standard of care you receive. Information on further sources of support will also be provided if required.

What are the possible benefits of taking part?

Although I don't expect that taking part will give you any direct benefits some people find talking about their experiences helpful. You might gain satisfaction at knowing that

the results of this study might influence and inform the care of patients in ICU in the future.

Will my taking part in this study be kept confidential?

All information, including tape recordings, researcher's notes, which are collected about you during the course of the research, will be kept strictly confidential. After consent is received, all research materials will be labelled with a code number and not your name.

What if there is a problem?

If you have any concerns about any aspect of this study you should ask to speak to the researcher who will do their best to answer your questions (Louise Stayt Telephone : 01793 437409). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details may be obtained from the John Radcliffe Hospital.

Who has reviewed the study?

My research supervisors from the RCN Research Institute, Professor Kate Seers and Dr. Liz Tutton, have reviewed the study. The study design has also been reviewed by the Oxford Research Ethics committee, the John Radcliffe NHS Research and Development department, a patient volunteer and an independent peer reviewer.

What will happen to the results of the research study?

If you would like a copy, a summary of the research results will be sent to you by post. The research results will be written up for my doctorate degree. It is also my intention to submit the research report for publication. I will also feedback the results of the study to the staff in ICU. Your anonymity is assured throughout. What you say will be combined with what other people say and you will not be individually identified. The research report may contain quotations but only if these can ensure anonymity.

Contact for further information

Thank you for reading this information sheet. Please do not hesitate to contact me, Louise Stayt, for any other information or queries.

Telephone: 01793 437 409

Email: lstayt@brookes.ac.uk

Postal Address:

Miss Louise Stayt,
School of Health and Social Care,
Ferndale Road,
Swindon, SN2 1HL

Further Information

If you would like general information about research within the NHS you may wish to visit the Involve website at:

<http://www.invo.org.uk/index.asp>

Or you may contact them at:

INVOLVE

Wessex House

Upper Market Street

Eastleigh

Hampshire

SO50 9FD

Telephone: 02380 651088

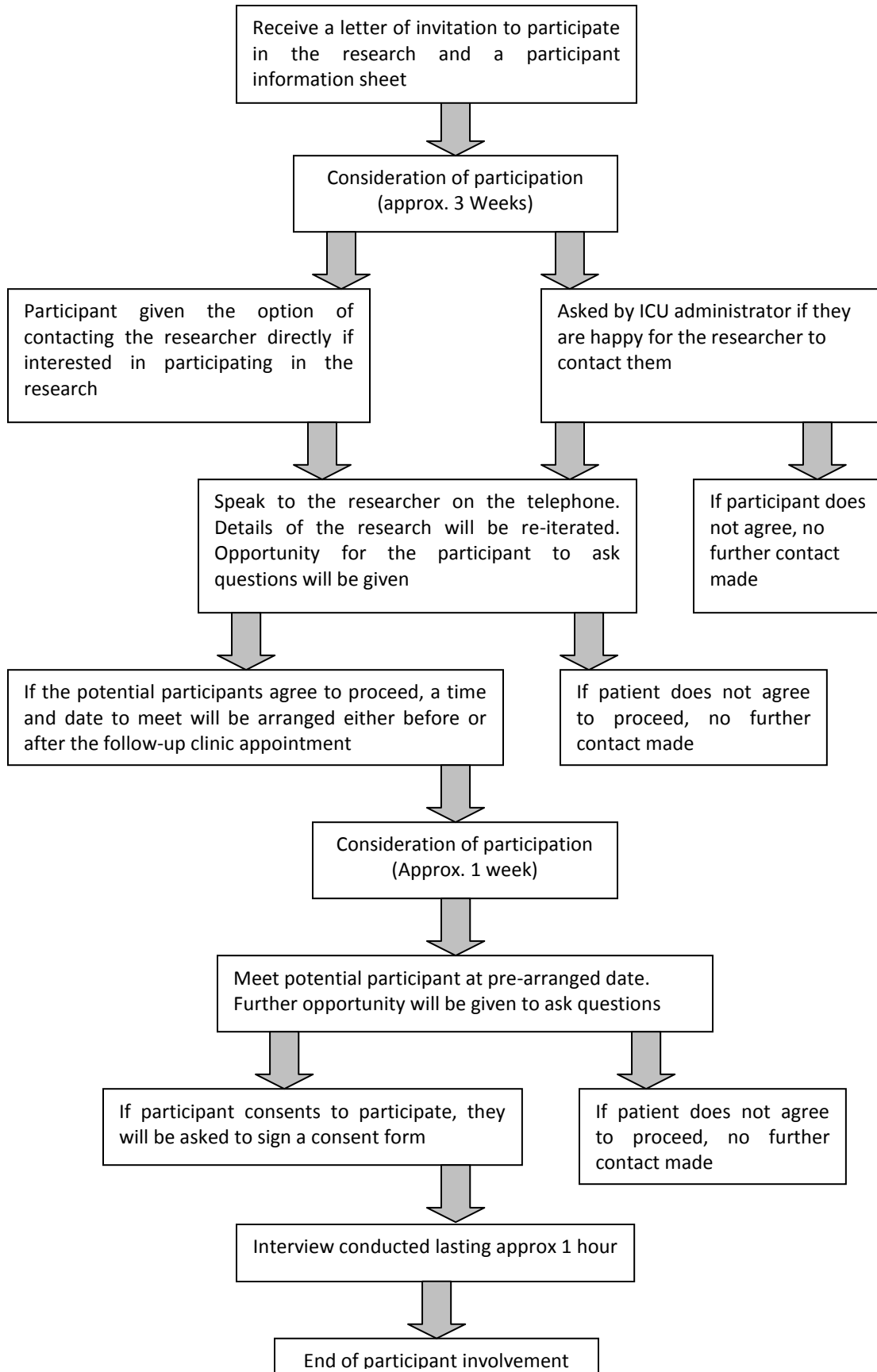
Textphone: 02380 626239

Fax: 02380 652 885

Email: admin@invo.org.uk

Appendix 3: Participant Flow Chart

Research Protocol: Participant Flow Chart



Appendix 4: Participant Consent Form



Participant Consent Form (Interview)

REC No: 09/H0606/66 Patients experiences of technology in adult intensive care

Investigator Louise Caroline Stayt

Project Site Follow-up Clinic, Intensive Care Unit, Critical Care Directorate, John Radcliffe Hospital

Please initial the boxes and print and sign your name at the bottom of this form

- 1. I confirm that I have read and understand the information sheet dated 15th May 2009, Version 1 for the above study.
- 2. I have had the opportunity to consider the information and discuss the project with others
- 3. I have had the opportunity to ask questions and have had these answered satisfactorily.
- 4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 6. I agree to allow anonymous quotations from my interview may be used in reporting of this study.
- 7. I agree to take part in the above study.

Participant Signature..... Date.....

Name (in block capitals).....

Investigator Signature..... Date.....

Name (in block capitals).....

Appendix 5: Interview Topic Guide

Interview Topic Guide

Admission to ICU

Example questions:

- What can you remember before you were admitted to ICU?
- What happened?
- How did you feel?
- What did you see/ hear/ feel/ smell?
- What treatments were you receiving?
- What machines and technologies were being used? E.g. oxygen, drips etc.

Experiences of being in ICU

Example questions:

- What do you remember about ICU?
- What happened?
- How did you feel?
- What did you see/ hear/ feel/ smell?
- What treatments were you receiving?
- What machines and technologies were being used?
- What can you remember about your interactions with health care professionals?
- Some literature suggests that nurses find it difficult in managing the technologies and caring for the patient. Was this your experience?
- Did you have any needs that weren't met?

Current Experiences

Example questions:

- How do you feel now?
- What were the positive aspects of your ICU admission?
- What were the negative aspects of your ICU admission?
- Did your feelings change over time?
- What would have made your ICU stay easier?

General Biographical Information

Age, diagnosis

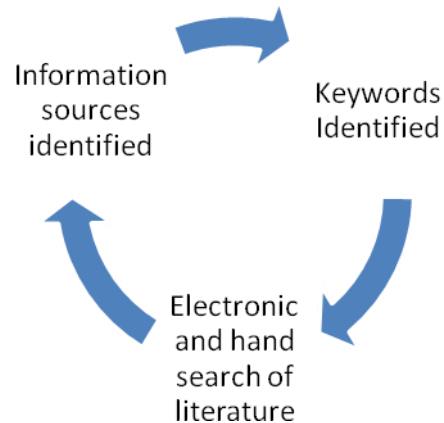
Length of stay in ICU

Time since discharge from ICU and from hospital

Appendix 6: Literature Search Strategy

Literature Search Strategy

An iterative and dynamic approach to the literature search strategy was adopted- as sources of information were identified, more relevant key words were selected. This resulted in more electronic and hand searches being conducted, more key words selected in a cyclical pattern.



Many keywords were used in many combinations multiple times throughout the five year period of study. This appendix details the general literature search strategy that evolved and gives a brief example of some of the keywords used.

Information Sources

The following databases were searched on multiple occasions throughout 2007- 2012:

- Medline
- CINAHL
- Web of Science
- PubMed
- Social Science Citation Index

The limits activated on these databases were: Humans, English, All Adult

The following journals were searched by hand to look for relevant articles:

- Nursing in Critical Care 2000-2012
- Intensive and Critical Care Nursing 2000-2012
- Intensive Care Medicine 2000-2012
- Critical Care Medicine 2000-2012

The reference lists of articles were also hand searched for relevant articles

Keywords

The following MeSH headings were utilised:

Technology	Nursing Research
Health care	Psychological Stress
Patients	Anxiety
Nursing	Communication
Nursing care	Noise
Professional Competence	Sleep
Critical care	Delirium
Intensive care	Post Traumatic Stress Disorders
Philosophy	Quality of Life

Other free text key words were utilised to narrow the search terms and mostly related to specific topics. Examples of free text search terms are as follows:

Phenomenology	Interviews
Grounded theory	Thematic analysis
Husserl	Ventilation
Heidegger	Tracheostomy
Body	Diaries

Various combinations of the keywords were combined using principles of Boolean Logic such as AND/OR

Where appropriate * and \$ truncations were used

Study Selection

Inclusion Criteria were as follows:

- Published literature only
- English Language Only
- Published 1900 onwards

Literature that did not meet the inclusion criteria was excluded.

The wide range of year of publication was utilised to capture early, seminal literature
Primary research utilising all methodologies and methods were included. In addition, discussion and opinion papers relevant to the topic area were considered for selection.

Titles of the retrieved literature were examined and those pieces of literature that were not relevant were discarded. The abstracts of the remaining literature were skim read and examined for relevance to the topic area. Again, those not relevant were subsequently discarded.

Appendix 7: An Extract from the Reflexive Diary

Notes on Interview Participant 5

Reflexive Diary Extract	Influence on data analysis
<p>Oesophagectomy and anastomotic break down. Sepsis. In and out of ICU. Really nice gentleman who was very open about his experiences. At first he was quite matter of fact. Very quickly opened up and described the more personal side. He described how he had been in and out of ICU as he had an oesophagectomy which broke down and ended up with a nasty sepsis. His first elective admission was only for two days and he said that he doesn't remember much about it. Later admissions he remembered really well which was quite surprising as he was intubated for quite some time. Different to follow up. Whilst in ICU needed to go to theatre for various procedures. In particular he was discussing the feeling of having an oesophageal stoma bag on his chest and being able to drink but see the fluid pass straight into the stoma bag. Whilst he was talking about it he described how he valued being able to drink even though it wasn't going any where as the dry mouth was the worse thing. Balancing the good with the bad? He also said that he found the whole thing quite disgusting when he thought about it. This made me think how I would feel- as though internal bits had been externalised and was visible on the outside- I think that I would find this disturbing too. I remember caring for a patient with a similar stoma. Due to the position it was really difficult to get a good seal around the stoma so it used to leak more or less constantly. The skin around the area therefore became really sore and the patient hated being damp. I used to hate it too as I never felt as though the patient was clean for very long. I remember thinking then that it would be awful as you basically have a bag of bile hanging around your neck. As Participant x was telling me his experiences I was picturing what it was like for the other patient. I specifically asked the participant how this made him feel and he said that he felt invaded. I can understand this feeling as it is not entirely obvious as to why this intervention is necessary- particularly if you are lay-person who may not understand the anatomical/ medical aspects.</p>	<div data-bbox="1036 394 1409 821" style="border: 1px solid orange; padding: 5px; margin-bottom: 10px;"> <p>I was always surprised by the amount that patients were able to remember as I assumed that they would have a very poor memory of events. This informed the theme of Making Sense of It where patients' memories were a patchwork of real, unreal and hazy memories together with complete gaps in their memory</p> </div> <div data-bbox="1036 1003 1409 1318" style="border: 1px solid orange; padding: 5px; margin-bottom: 10px;"> <p>The feeling that the patient was balancing the good with the bad informed the development of the theme Necessary Evil. This highlighted some of the physical stressors encountered</p> </div> <div data-bbox="1036 1480 1409 1795" style="border: 1px solid orange; padding: 5px;"> <p>The feeling of disgust and despair and feeling invaded by the interventions informed the development of the concept of enforced injuries and the theme Being Invaded. It also highlighted how central the body was to patients' experiences</p> </div>