

A grounded theory study exploring critical care staff experiences of approaching relatives for organ donation

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“For a dying man it is not a difficult decision [to agree to become the world's first heart transplant recipient] ... because he knows he is at the end. If a lion chases you to the bank of a river filled with crocodiles, you will leap into the water convinced you have a chance to swim to the other side. But you would not accept such odds if there were no lion”

(Christiaan Barnard, 1967).

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Dedication

“Adam, your life was extinguished far too soon but your story will always remain with me both personally and professionally. I dedicate this thesis to you and the legacy you left behind. Eternal rest grant him, O Lord, and let perpetual light shine upon him. May he always Rest In Peace”.

I dedicate this thesis to all organ donors who have altruistically and benevolently donated organs to help other people. Each of you has your own story, each an inspiration, and you will never be forgotten.

List of Abbreviations

AMRC	Academy of Medical Royal Colleges
BSD	Brain Stem Death
CLOD	Clinical Lead in Organ Donation
CGT	Constructivist Grounded Theory
DBD	Donation following Brain Stem Death
DCD	Donation following Circulatory Death
DH	Department of Health
*DTC	Donor Transplant Co-ordinator
ED	Emergency Department
EDHEP	European Donor Hospital Education Programme
EoLC	End of Life Care
GMC	General Medical Council
GT	Grounded Theory
NHS	National Health Service
NHSBT	National Health Service Blood and Transplant
ICH	Intra Cranial Hemorrhage
ICS	Intensive Care Society
ICU	Intensive Care Unit
NICE	National Institute for Clinical Excellence
NMC	Nursing and Midwifery Council
NHBD	Non Heart Beating Donation
OD	Organ Donation
ODR	Organ Donor Register

ODT	Directorate of Organ Donation and Transplantation
ONS	Office for National Statistics
PDA	Potential Donor Audit
R&D	Research and Development
RCN	Royal College of Nursing
SNOD	Specialist Nurse in Organ Donation
UK	United Kingdom
UKDEC	United Kingdom Donation Ethics Committee
UKT	United Kingdom Transplant
WLST	Withdrawal of Life-Sustaining Treatment
*DTC	Donor Transplant Co-ordinator: Professional title changed in 2009 to become Specialist Nurse – Organ Donation (SNOD)

Definition of Terms

Academy of Medical Royal Colleges: AMRC speaks on standards of care and medical education across the UK. By bringing together the expertise of the medical Royal Colleges and Faculties, it drives improvement in health and patient care through education, training and quality standards.

Brain Stem Death (BSD): A patient who has been certified as dead following brain stem death testing criteria.

Clinical Lead for Organ Donation (CLOD): A consultant clinician who provides support and training within the donor hospital, acting as a champion to embed donation as a normal part of end of life care. Typically, NHSBT pay 1-2 PA's of Consultant time.

***Critical Care Staff / Professional:** A registered nurse or medical doctor working in a critical care unit.

Emergency Department (ED): Historically known as the Accident and Emergency (A&E) or Casualty, the department provides care for patients with both minor and major illness / disease.

Intensive Care Unit (ICU): Sometimes referred to as the Intensive Therapy or Critical Care Unit. This is a specialist unit that provides care for critically unwell patients who experience multi organ dysfunction due to injury and / or illness.

National Health Service Blood and Transplant (NHSBT): Is a Special Health Authority, dedicated to saving and improving lives through the wide range of services provided to the NHS.

Nursing and Midwifery Council (NMC): The regulatory body that maintains a register and upholds professional standards for all nurses and midwives in the UK.

Organ Donor / Donation: A person who has donated their organs and / or tissues following death for use in transplant operations.

Specialist Nurse in Organ Donation: A nurse who has been trained to facilitate all aspects of the organ donation process.

Withdrawal of Life-Sustaining Treatment (WLST): The process of stopping or ending life sustaining treatment on a patient being cared for in the Intensive Care Unit. This is normally a multi professional decision, led by the medical Consultant based upon a decision of futility.

***Critical care staff / critical care professional / critical care doctor / nurse are terms that are used interchangeably throughout the thesis.**

Thesis Abstract

Aim of study: This grounded theory study explores critical care staff experiences of approaching relatives for organ donation following the death of a patient.

Background: The research was influenced by a startling statistic that reported an average 1,000 patients die each year on the transplant waiting list because no suitable organ donor was identified. Additionally, transplant operations are impeded by a significant family refusal rate for organ donation. Some of the reasons are known why relatives / carers decline the option of organ donation. It is unclear how the experiences, perceptions and beliefs of critical care professionals influence organ donation decisions and outcomes. This study seeks to explore the professional experiences in greater detail, generating new knowledge and the development of a conceptual framework to support the practice of critical care staff during the organ donation process.

Methods: A grounded theory methodology was used to help guide the research design and process. Specifically, constructivist grounded theory developed by Kathy Charmaz (2006) became the theoretical basis used to conduct the research. Ethical approval was granted by the University of Salford, NHS Blood and Transplant and the hospital trust where the study was conducted. Sampling was purposeful and data were extracted using a series of semi-structured in depth interviews with critical care professionals (6 registered nurses and 2 registered medical practitioners: N = 8). Interview data were transcribed line by line and analysed using grounded theory methods, with an iterative process encouraging the detection of links and themes in the data.

Findings: Four theoretical categories were developed as a result of the data analysis process. The categories include 'Secrecy', relating to critical care staff concerns that the organ donation process is secretive, 'Mutilation', connected to the belief that the patient could be harmed following death, 'Broaching', concerned with critical care staff fear surrounding donation discussions and 'Experiential Competence' which encompasses critical care staff competence associated with organ donation. The core category entitled '*Fear*' is presented, which leads to the development of a substantive theory. Additionally, a conceptual framework was developed, centred on the core category, which was constructed to increase the likelihood of positive donation outcomes.

Conclusion: Having explored critical care staff experiences of organ donation following the death of a patient, the study concludes that '*fear*' influences professional practice at each stage of the donation process. A number of recommendations for practice arise from the study findings. Equally, the study suggests areas for further research and post-doctoral inquiry.

Thesis Structure

This thesis has been constructed for the award of Professional Doctorate (DProf) in Health and Social Care. The thesis is presented over six Chapters. **Chapter 1:** Provides an introduction to the thesis, overview of the research and personal and professional location of the researcher. In addition, a background narrative is provided on organ donation which helps to contextualise the research. The concepts of death and dying are explored which is the starting point for organ donation. **Chapter 2:** Provides a narrative review of the evidence and research that has gone before, assisting in the identification of gaps within the body of established knowledge. Following the narrative review, the chapter progresses to critically analyse the selected evidence sources which help to shape the original contribution that the thesis offers. **Chapter 3:** The methodological approach that was employed for the research study is discussed within this chapter. This helps the reader to appreciate the data collection method, sample size and selection, and ethical considerations that were observed during the study. **Chapter 4:** Critically explores the data analysis process that was applied following data collection. The data coding process is explicated using the analytical process advised by Charmaz (2006). **Chapter 5:** The findings from the study are explicated in this chapter. To ensure transparency in theoretical category development, examples of the selective coding process, use of reflective memos and abstract situational mapping are provided. Additionally, a discussion of four theoretical categories are integrated in the chapter, supported by an underpinning of theoretical perspectives and evidence. Finally, the core category entitled '*Fear*' is presented which leads to the development of a conceptual framework. **Chapter 6:** This final chapter presents personal reflections, recommendations for practice, limitations of the study and conclusion.

Chapter 1: The Research Context

1.1 Introduction to the Thesis

As a former critical care nurse and Specialist Nurse - Organ Donation (SNOD), this chapter was influenced by personal thoughts and professional experiences of approaching relatives for organ donation. In addition to experiences as a registered nurse, the taught element of the professional doctorate encouraged extensive personal reflection and provided an ideal platform to begin writing this chapter. The cathartic process of critical reflection allowed recognition of how such experiences have shaped the thesis and personal location in the research. Developing this chapter allowed me to situate myself in the research and orientate the reader to the background of the study. Revealing my own personal reflective thoughts and assumptions ensures transparency in the research process thus adding credence to the thesis. Firstly, I describe personal beliefs relating to organ donation and transplantation. Next I explore the professional experiences of organ donation which helps the reader to understand personal ontological assumptions. The chapter also examines transplant statistics which provides a rationale for the study and highlights the need for more organ donors. Finally, emotive concepts of brainstem death are explained which help to contextualise the research.

Most organs of deceased donors originate from patients being cared for in critical care areas such as the Intensive Care Unit (ICU) and Emergency Department (ED) (Citerio *et al*, 2016). Consequently, it is the critical care professionals in these specific clinical areas who manage the organ donation process. This thesis presents a grounded theory (GT) exploration of the experiences of critical care staff approaching relatives for organ donation following the death of a patient. Organ donation is reported to be an emotive concept that challenges personal and professional beliefs and practice (Meyer, 2011; Lloyd-Williams, 2009; Streat, 2004). Critical care professionals have an important role in the organ donation process because they are

present during end of life decisions, refer potential organ donors to the organ donation team and are instrumental in initiating the organ donation discussion with relatives / carers (Garside and Garside, 2010).

The experience of critical care doctors and nurses when the care trajectory moves from saving life to end of life care (EoLC) is a poorly understood phenomenon. The aim of this study was to explore the experiences of critical care staff regarding organ donation in order to develop better understanding about and develop new theory. The main aim for this research study is supported by three associated objectives, described below:

Research aim: A grounded theory study exploring critical care staff experiences of approaching relatives for organ donation

Associated objectives:

- To develop an understanding of the key factors that critical care staff feel influence relative / carer decisions to donate organs for use in transplant operations
- To determine whether critical care staff's own experiences / perceptions / belief have influenced their conversations with the relatives / carers of dying patients and potential organ donors
- To develop new knowledge and theory about how critical care staff can best support the relative / carer decision regarding organ donation when caring for a potential organ donor

1.2 Researcher in context

This section provides an overview of the pragmatic epistemological underpinning that helped shape my study. I write the thesis deliberately in the first person, enabling expression of personal ideas and thought. I argue this approach is needed to contextualise the research and the reason for conducting the study. Some scholars prefer the use of third person in academic writing (Oliver, 2014). However, this perspective would not allow true expression of personal feelings and emotion. I believe that writing in first person helps with the co-construction of social reality, a belief consistent with the constructivist grounded theory approach underpinning my research (Craswell and Poore, 2012; Charmaz, 2007).

“For grounded theorists, a story does not stand on its own. Instead, we use stories in service of our understanding. Voice echoes the researcher’s involvement with the studied phenomena”

(Charmaz, 2006: p175).

In 2009 I made the decision to join the Roman Catholic faith. Originally a member of the Church of England, it didn’t feel right that I could not receive Holy Communion with my wider family. My faith is important to me and shapes the person I am and what I think. As described by Foucault (1982), faith “*designates a very special form of pastoral power*” (p 783) and has, arguably, affected my thought process regarding organ donation. For example, it is my belief that organ donation is the altruistic giving of self to help others, which is a belief consistent with my faith. Foucault (1982) would argue that this belief may be considered as a way to salvation. Furthermore, within his writing, Foucault (1982) explores the meaning of the term “*salvation*” (p 784) and contends it doesn’t necessarily relate to the next world but ensuring it in this world. I argue that “*salvation*”, in this context, could be perceived in alternative ways including discussing my organ donation wishes with family during life and joining the National Health Service (NHS) Organ Donor Register (ODR).

That is to argue that if I need an organ transplant from another human being then I should be prepared to donate my own organs to others following death.

1.3 Professional experience of organ donation in context

Charmaz (2006) proposes that “*the research journey begins before the traveller departs*” (p 1), therefore it is prudent to begin by exploring my professional background and development of my research interest. My first professional experience of organ donation is presented as a case scenario based on real events. In addition, this section includes theory which is explored and integrated into the account which allows the professional context to emerge. In a similar way, de Sales Turner (2006) discusses the power that story telling has to shape the individual and collective conscious of nursing. Furthermore, de Sales Turner (2006) suggests that “*telling stories from the field*” encourages critical reflection on professional practice (p 93).

During 2001, whilst employed as a staff nurse in the Intensive Care Unit (ICU), I witnessed my first organ donation from a patient at the end of life. Jayne (pseudonym) died from an intra cranial haemorrhage (ICH) at the age of 38, leaving behind a devastated husband, two young children, mother and siblings. Following completion of the brain stem death tests, the ICU consultant declared death and requested the on call Donor Transplant Co-ordinator (DTC) be contacted, allowing the subject of organ donation to be broached with the family.

Jayne was left on mechanical ventilation and her organs were supported with vaso-active medicines, she looked like she was asleep. Her skin was pink, warm to touch, chest rising and falling with each volume of air delivered by the ventilator. The family requested time, prior to removal of ventilation, so they could inform Jayne’s children, who had gone to school as

usual, that mummy had died. Personal grief, profound shock and anxiety at the impending donation discussion were three emotions I experienced as the bedside nurse.

At that time, I felt ill prepared to deal with the needs of the grieving family and sadness that Jayne had died. The critical care team couldn't do anything to save her and I experienced deep sadness that, at this time, I believed that organ donation would add further stress and anxiety to the family. The on call Donor Transplant Co-ordinator (DTC) arrived and immediately greeted the family at the bedside. "*Do we have somewhere we could talk in private*", she asked me. Moving to the ICU relative's room, the DTC employed unbelievable skill in assessing if the family were ready for the organ donation question. This skill included allowing time, pacing the delivery of information to meet the needs of the family and communicating in simplistic terms. By ensuring the family had accepted that death had occurred, the option of donation became an immediate positive with Jayne's husband lifting his head for the first time during the conversation. "*Yes, she would want that to happen*".

This experience transformed my personal belief and attitude towards organ donation. From initial apprehension about the planned organ donation, my observation of the professional demeanor displayed by the attending donor transplant co-ordinator (DTC) offered reassurance that the process was conducted with utmost respect and dignity. Seemingly, the organ donation decision belonged to Jayne's family and no-one else. I thought that the organ donation request would add further stress to an already fragile family. However, as the organ donation process developed, it was clear to see the enormous amount of comfort the option of donation was providing for the family. The family had placed their implicit trust in a stranger, hoping she would provide care and dignity throughout the organ donation process. I now concur with Fredriksson and Eriksson (2003) that organ donation is an altruistic act and the DTC, through a caring conversation, altruistically gave 'herself' to alleviate suffering.

Reflecting on the conversations between the DTC and the family, the donation discussion was constructed by a sequence of co-constructed narratives (Gadow, 1996). Sally Gadow (1996), as a nurse philosopher, describes “*ethical narrative*” as the centre of the nurse-patient relationship. Gadow conceptualised ethical narrative as:

“Among many types of narrative relevant to nursing, ethical narratives have a central importance, they tell us why we practice. An ethical narrative portrays the value aspect of a situation, the good that is being sought by patient and nurse”

(Gadow, 1996; p 8).

Similarly, Hess (2003) developed the work by Gadow arguing that professional knowledge, education and construct of the professional role has great influence on the patient-nurse relationship. Moreover, Hess (2003) advances the theory further stating that nursing professionals are socialised into particular roles with associated role performance norms and expectations. Assuming that ethics are grounded in relationships, then the nurse caring for the potential organ donor (and donor family) must be facilitated by a shared *relational* ethic.

Gadow (1996) concludes that the relationship between the nurse and patient [relative / carer] is an ontology, a way of being. If Gadow’s (1996) theory is applied to the organ donation context, I argue that both the nurse and relative have to work hard to establish effective communication networks which enable positive donation outcomes.

Jayne and her family became a defining experience which shaped my later practice and developed my interest in organ donation. Over the following six years, I acted as a link nurse with the local organ donation team, attending conferences and supporting initiatives to promote organ donation. In 2007, I was successfully appointed as a Donor Transplant Co-ordinator (DTC) for the North West region. Initially, this was a dual role responsibility meaning both donor and recipient duties. The recipient component of the role, at that time, included the listing and care of patients requiring kidney and pancreas transplantation at a

large University teaching hospital. The donor part of the role was providing an on call service to the entire North West as a Specialist Nurse in Organ Donation (SNOD). This included meeting patients at the end of life and supporting acutely grieving families on the ICU, offering the option of organ donation as appropriate. If the family consented to organ donation, I then facilitated all aspects of the donation process including donor care. The role of SNOD can be related to Gadow's (1996) *relational* ethics as it is connected with the concept of beneficence and "*the good constructed by patient [donor family] and nurse*" (Hess 2003; p 139).

It is acknowledged that during organ retrieval surgery, the patient remains a 'receiver of care' with specific care needs following the operation (Griffin, 1983). Furthermore, Griffin (1983), who explored a philosophical analysis of caring in nursing, asserts that nurses must imagine the patient as an autonomous person, responsible for his/her own action. However, I assert this is particularly challenging for the critical care nurse to imagine, as the patient has been unconscious during the period of critical illness. Therefore, as Griffin (1983) argues, the autonomy of the person has been relinquished which produces a situation where the individual is unable to express personal needs and beliefs. This is significant as the critical care nurse is unable to know the true identity of the patient, the "*whole person*" is hidden and the nurse, as a care giver, becomes the "*protector of humanity*" (Griffin, 1983: p 291).

Consequently, the nurse and relative have to make assumptions about the patient's wants, desires and priorities. The concept of caring, as discussed by Griffin (1983) illustrates that the giver of care [nurse] experiences a myriad of emotional and moral assumptions concerning the receiver of care [patient]. This is worthy of greater exploration as it is unknown whether the emotional components of caring influence decisions made by potential donor families. This is an important element to consider given the refusal rate by relatives for organ donation is 40% (NHSBT, 2017).

Reflecting on Jayne and her family seventeen years ago, I was left with many questions remaining:

- What was it that made the critical care team want to engage with the organ donation?
- What influenced the family to consent to organ donation?
- What caused my initial anxiety about the proposed organ donation?
- To what extent does the ethical narrative influence decision making regarding organ donation?

As a specialist nurse – organ donation, I wanted to explore the experiences of critical care staff to determine if they influence the decision made by potential donor families to donate organs. Embarking on the professional doctorate in 2012 was the first step to resolve unanswered questions from practice. This thesis is a journey seeking to understand the complex issues faced by critical care staff when confronted with organ donation following the death of a patient in their care.

I have grappled with the tensions of how researchers embrace or attempt to remove their personal experiences from the research process and I have attempted to explicate this through careful reflection on my research. I acknowledge that my personal assumptions have had a powerful impact and these are recognised in that my beliefs have the potential to influence the research. Foucault (1982) discusses this in his writing *The Subject and Power*:

“How, not in the sense of ‘How does it manifest itself?’ but by what means is it exercised? And what happens when individuals exert (as they say) power over others”

(Foucault, 1982: p 786).

Foucault's (1982) principles of power are reflected in professional power and his philosophy can be applied to the request for organs. It is possible that if critical care professionals exert power and control over their attitude towards organ donation, it is worth exploring whether this "power" influences the donation outcome.

Ontology is a term that originally derives from theology, and is concerned with the nature or essence of things (Wellington *et al*, 2012). My ontological assumptions about social reality focus on my experience of being human and my belief that the social world is socially constructed. However, if I viewed the social world as given, it would be my belief that it can be tested and accounted for through objective, quantifiable data. If this were the case, I would adopt a positivist, quantitative and experimental methodology to test my research question.

However, I have adopted a social constructivist position and it is known that organ donation is an emotive and sensitive subject (Bleakley, 2017; Meyer, 2011; Lloyd-Williams, 2009; Streat, 2004). Therefore, I believe, it is necessary to collect subjective accounts and perceptions to explain the world as experienced by critical care staff because of the depth of human emotion attached to organ donation (Craswell and Poore, 2015). Epistemology is the theory of knowledge thus epistemological assumptions are connected with *how we know*, within the nature of knowledge, and what constitutes knowledge (Oliver, 2014; Wellington *et al*, 2012; Charmaz and Bryant, 2007). Consistent with my assumption that knowledge is socially constructed, my methodological choice [constructivist grounded theory] is concerned with asking questions and exploring experiences of the people involved in the study.

My epistemological assumptions are essentially concerned with the ways in which human beings (critical care staff) act in the socially constructed world. Furthermore, Blumer (1969) suggests humans can only respond to things within a social world based on the *meaning* attached to them. This is demonstrated within his seminal writing *Symbolic Interactionism*

which, as a constructivist, is a credible theory to explicate human life and human conduct (Blumer, 1969). That is to argue that I have always understood organ donation to be a positive action but I am curious why some people may not share this belief, hence a high family refusal rate. The next section explores the current organ donation and transplant statistics which highlights the need for more organ donors.

1.4 Organ Donation and Transplant Statistics

In order to contextualise the research and provide rationale for conducting the study, transplant statistics are examined. Additionally, a definition of organ donation is provided thus allowing the statistics to be framed in a meaningful context. The potential for organ donation in the United Kingdom (UK) is explored through a detailed inspection of the Potential Donor Audit (PDA). Both the transplant statistics and PDA illuminate a critical shortage of donated organs, adding credence to the proposed study. Moreover, the PDA reports a refusal rate of relatives permitting organ donation of 40%.

Organ donation can be described as the altruistic giving of an organ to someone who needs a transplant (NHSBT, 2016; Citerio *et al*, 2016). According to National Health Service Blood and Transplant (NHSBT, 2017), there were 6388 patients listed for organ transplant by the end of March 2017 (NHSBT, Transplant Activity Report 2017; Appendix 3). However, further scrutiny of the report reveals this figure does not reflect the true number of patients waiting for a transplant. For example, in addition to the active 6388 patients on the waiting list, 3357 patients had been temporarily suspended. Temporary suspension from the waiting list means that the clinical condition of some patients had deteriorated and the proposed transplant would be unsafe (NHSBT, 2017). During the financial year to 31st March 2017,

457 patients died while on the active waiting list. The total number of organ transplants performed during the same financial year was 4,753.

These figures demonstrate that the demand for transplant far outstrips the number of donated organs. There is a critical shortage of donated organs, year on year, meaning that patients have to wait longer for their transplant operations and some will die whilst waiting (NHSBT 2017; Lin *et al*, 2014). A comparison of the Transplant Activity Report from 2001 (16 years previous) exhibits a recurring characteristic, more patients listed for transplant than donated organs available (Transplant Activity Report 2001; 2017). During the financial year 2001-2002, 6,842 people were listed for a transplant whilst 2,717 organ transplants were performed.

Around 5,000 people die each year in circumstances where organ donation is possible (NHSBT, 2017; Appendix 2). A small group of patients who die in specific situations within the Intensive Care Unit (ICU) or Emergency Department (ED) may be eligible to donate organs (Manara *et al*, 2012; DH 2008; ICS, 2004). Organ transplantation is the only therapeutic option for terminal organ failure (Citerio *et al* 2016; Monforte-Royo and Roqué, 2012). It is a small proportion of deaths within critical care areas that can be identified as potential organ donors. Organ donation occurs in three different forms which are introduced and described below. Essentially, organs can be considered for donation in different care contexts, this is significant because two forms of donation occur within the critical care setting.

1.5 Types of organ donation

The three forms of organ donation include Donation following Brain Stem Death (DBD) or following Circulatory Death (DCD) or Live Donation. Donation following Brain Death (DBD) is a situation whereby a person ceases to have any brain stem function, normally following a neurological injury such as a Traumatic Brain Injury (TBI) or an Intra Cranial Haemorrhage (ICH). The person has permanently lost the capacity to breathe and a mechanical ventilator artificially keeps the heart beating, providing oxygenated blood to organs (Bleakley, 2017). Brainstem death is explored in more detail later in this chapter.

Donation following Circulatory Death (DCD) is a type of donation whereby the heart has stopped following cardiac arrest and cannot be successfully restarted. Equally, this type of donation can arise following the planned withdrawal of life-sustaining treatment (WLST) of patients in ICU or ED. Donation following Circulatory Death (DCD) is explored in more detail later in this chapter.

Live donation is a type of donation whereby the person is still alive and makes the altruistic decision to donate a kidney, small section of the liver, discarded bone from a knee or hip replacement or the placenta following birth. In this context, the donor and recipient are prepared and have time to make informed decisions prior to surgery. Despite the potential to save life through the three forms of organ donation, many relatives withhold consent (40%) presenting a significant barrier to organ transplantation (NHSBT 2017; Barber *et al*, 2006).

The deaths associated with organ donation are often sudden and unexpected such as trauma and sudden intra cranial haemorrhages. Glaser and Strauss (1965) explored *Awareness of Dying* and the strategies that nurses employ to maintain composure as a patient approaches death. They discovered that if the death is really unexpected, as with most cases regarding the

potential for organ donation, nurses have “*no death expectation at all, they have no strategies to maintain composure*” (Glaser and Strauss, 1965: p 251).

Furthermore, Glaser and Strauss stated that a sudden death is particularly upsetting for nurses because it could imply they have been negligent in nursing care. Organ donation occurs following the death of the patient but, as Glaser and Strauss (1965) identify, the nurse is left wondering if things could have been done differently to save life. The work by Glaser and Strauss (1965) provides further evidence regarding the complexity of death and dying and how it is interpreted by nurses and doctors. Exploring the death and dying of patients, as experienced by critical care staff, may provide critical information regarding the factors that influence donation discussions.

Analysis of the Transplant Activity Report (2017) reported that the UK has an overall population of 64 million. During the financial year 2016-17, the UK had recorded 576,000 deaths (ONS, 2016). A total of 290,000 of the recorded deaths occurred in hospital, of which 7,024 were potential organ donors. However, once preclusions to organ donation had been applied (blood born malignancy / multi organ failure), the total number of eligible donors falls to 5,681. The organ donation request was only made in 3,144 of the eligible donors, resulting in 2,082 consented donors. A consented donor is described as the family being asked for their lawful and written consent for their relative to donate organs and they agreed (NHSBT, 2017; Human Tissue Act, 2004). The key problem with the Transplant Activity Report is it fails to identify, in any great depth, the reason why out of 5,681 eligible donors, only 1,282 patients became actual donors. Further inspection of the national Potential Donor Audit (PDA) is essential so that these statistics can be placed in a meaningful context. The reasons why so many refuse organ donation needs careful consideration because a high family refusal rate inhibits transplant operations.

Interestingly, England, Scotland and Northern Ireland have actively begun consultation on the impact of an Opt-Out system for organ donation (DoH, 2017). This system would mean that the deceased is a ‘presumed’ [sic] organ / tissue donor unless they have actively Opted-Out of becoming a donor. The current system in the UK (excluding Wales) observes an Opt-In policy, relying on registration and donor card system operated by NHS Blood and Transplant (NHSBT). However, the Welsh Opt-Out law changes in 2015 failed to dramatically increase the number of organ donors. For the preceding year prior to implementation of the legislative changes, Wales had a total of 101 organ donors (Hawkes, 2017). The corresponding year, after the law changed to an Opt-Out system for organ donation, a total of 104 people donated organs. Under the Human Transplantation (Wales) Act (2013), “*the agreement of next of kin must still be sought, a condition missed by many*” (Hawes, 2017: p 1). These figures provide evidence that law changes alone are an unsuccessful method of significantly increasing donor numbers.

The Potential Donor Audit (PDA) is a national audit conducted by the Specialist Nurse – Organ Donation (SNOD) on behalf of NHS Blood and Transplant. This audit is significant as it provides essential data on patient outcomes following death related to organ donation. This audit collects demographic data on every patient that dies in critical care areas (ICU and ED) combined with reason for admission, length of stay in the critical care area, cause of death and whether the patient had brain stem death tests completed or whether active treatment was withdrawn.

The PDA includes all audited deaths in UK intensive care units (ICU) and emergency departments (ED) for the year 1st April 2016 – 31st March 2017. Interestingly, any patient over the age of 80 years has been excluded from the report but there are patients nationally that have donated kidneys and liver beyond 80 years of age (North West Key Performance

Indicators Data, 2015). The number of patients at this mature age who donate organs is small but the PDA does not reflect this, thus demonstrating inaccuracy.

There is a distinction between donation after brain death (DBD) and donation following circulatory death (DCD) which is explained in greater detail later in this chapter. Of the eligible donors whose family consented to organ donation, 91% of the eligible DBD donors and 47% of the eligible DCD donors went on to become successful organ donors (NHSBT, 2016).

For consented DBD donors, the main reason provided for organ donation not proceeding was the organs had been declared medically unsuitable (47%) and declined during surgical inspection (13%). Similarly, for DCD donors the main reason for consented donors not proceeding (42%) was a prolonged time to asystole (PTA) following withdrawal of life sustaining treatment (WLST) (Potential Donor Audit, 2015). Prolonged Time to Asystole (PTA) is the situation when life sustaining treatment has been withdrawn but the heart continues to beat for a prolonged period of time meaning the organs become irreversibly damaged. In this situation, the opportunity for organ donation elapses and transplantation is not possible.

The Transplant Activity Report (2017) did not show any statistical significance between consent rates for males and females for DBD and DCD. Conversely, the report did show statistical significance difference in both DBD and DCD consent rates from patients identified as white opposed to patients from the black and minority ethnic (BAME) groups. Despite making this remark, the Transplant Activity Report (2016) did not provide any numerical data / table to discuss this observation in more detail.

Whilst the PDA collates vital information to support the planning of the organ donation strategy, it fails to detect reasons why the UK observes a significantly high family refusal

rate. Perhaps the greatest disadvantage is that the PDA data does not capture the conversations that critical care staff have with potential donor families. The experiences and perceptions of critical care staff are not reflected in the PDA and further exploration is needed to determine if critical care staff influence decisions made by potential donor families. The starting point for the organ donation is the death of a person and death, as a concept, warrants further analysis. This is significant as critical care staff interaction, following the death of a patient, may influence the decision making process of relatives relating to organ donation.

1.6 The challenges with the Diagnosis of Brainstem Death

Deceased organ donation falls into two categories; Donation following Brain Death (DBD) and Donation following Circulatory Death (DCD), (NHS Blood and Transplant, 2014). In the UK there is no statutory or legal definition of death (Doran, 2004). Secondly, given that there is no definition of death, courts accept death of the person based on specific criteria inferring the person is dead (Bleakley, 2017; Hendrick, 2000). Brain stem death, as a concept, originated in the UK in 1976 following a Conference of Medical Royal Colleges, based on specific criteria (which if met, signified legal death of the person) (Academy of Medical Royal Colleges, 2008).

Most deaths are confirmed as a cardiac death, meaning the heart stops beating, breathing ceases and the pupils become fixed and dilated. Following examination of the deceased body and performing validated tests to prove death has occurred, the qualified medical practitioner is able to pronounce death (GMC, 2015). However, there are clinical situations that blur the lines regarding the diagnosis of death such as heart transplant surgery (Doran, 2004). It is routine for a heart transplant recipient to have the diseased heart removed, be placed on

cardiac bypass in preparation for the incoming healthy donor heart. For a short period of time, the recipient has no myocardium until the donor heart is transplanted. The absence of a heart beat is part of the criterion for confirming a cardiac death but the patient is not dead in this scenario. This example provides evidence that the diagnosis of death is complex with many potential ethical dilemmas, especially with no legal definition to support clinical practice (Monforte-Royo and Roqué, 2012).

Having explored cardiac death as a concept, this section advances to explore the inherent tensions that exist when declaring brain stem death. If certain preconditions have been fulfilled, clinicians can instigate formal brain stem death testing. The UK requirement is that two sets of tests are performed by two separate doctors, one must be a Consultant and both must have been registered with the General Medical Council (GMC) for more than five years (AMRC, 2008). On completion of the brain stem death tests, the doctors sign and date and time the brain stem death form (AMRC, 2008). Clinically, the patient is left being artificially supported on a ventilator having been declared dead. The ventilator will allow the chest to rise and fall, the skin is pink and warm to touch, giving the illusion that the patient is asleep or has the capacity to regain consciousness (Bleakley, 2017; Pearson *et al*, 2001). The situation of a dead patient being artificially supported is traumatic for both bedside relatives and the bedside nurse (Lloyd-Williams *et al*, 2009). At this point, the ethical narrative “*the good that is being sought*” between the nurse and relative may be inhibited due to profound shock and grief (Gadow, 1996: p 8).

However, many years after the advent of formal brain stem death testing criteria, questions have been raised as to the medical understanding of the concept of brain stem death. Bell *et al*, (2004) conducted a study investigating the knowledge base of 240 consultants that worked in neuro-anaesthesia critical care. The response rate to the questionnaire was 65%, with 70% of respondents performing brain stem death tests more than 5 times per year. It was clear that

ambiguity surrounded brain stem death testing; 19% of respondents did not assess whether there was any endocrine disturbance. For example, profound hypernatraemia (high serum sodium) or hypoglycaemia (low serum glucose) can induce the clinical signs of coma and mimic the coma associated with brain stem death.

Medical uncertainty by critical care staff regarding brain stem death as a concept, equally the societal and psychological complexity of organ donation, mean it is feasible that consent rates for organ donation are affected (Bleakley, 2017; White, 2003; Young and Matta 2000, Wace and Kai 2000, Powner *et al*, 1999). The frequency of spinal reflex movements in brainstem dead patients can create difficulties in both clinicians and families not familiar with the pathology of brainstem death (Bleakley, 2017; Döşemeci *et al*, 2004). Spontaneous movements and reflexes do occur in certified brainstem dead patients, originating in spinal cord neurons. If the clinician fails to explain the reason for spinal reflex movement to the family, or indeed fails to understand the pathology him/herself, it may inhibit the starting of organ donation discussions (Bleakley, 2017; Döşemeci *et al*, 2004). This section illustrates that brain stem death is a contentious issue for critical care staff (Monforte-Royo and Roqué 2012; Lloyd-Williams *et al*, 2009; Pearson *et al*, 2001). Further exploration of perceptions and experiences of critical care staff related to brain stem death will promote a better understanding of the key issues that may influence donation outcomes.

1.7 Chapter summary

It is clear that critical care professionals face many moral, ethical and professional issues with not only organ donation but the diagnosis of death. Key issues concerning power, grief response and statistical rhetoric from transplant authorities appear to have considerable impact on nursing practice. This introductory and background chapter has situated the research into a meaningful context. Sharing my personal location and motivations related to organ donation demonstrates how the research interest and research question has emerged. Even before organ donation is a possibility, it is acknowledged that critical care staff encounter a complex situation when a patient is diagnosed as brainstem dead. Equally, I have explored some of the key issues but further research is needed to investigate whether critical care staff experiences influence organ donation decisions and outcomes. This thesis is the start of a journey to develop new knowledge on this important clinical subject.

Chapter 2: Narrative Review of the Literature

2.1 Introduction

This chapter provides an overview of the literature connected to the study. The study is primarily concerned with critical care staff experiences of approaching relatives for organ donation following the death of a patient. A rationale for selecting a narrative review as part of the grounded theory study is explicated. The key stages of the narrative review design are explained using the framework as advised by Ferrari (2015). Finally, the chapter presents the narrative review findings, identified themes and discussion.

2.2 Rationale

In grounded theory studies, there is a widely accepted view that the researcher should be invisible and become a 'tabula rasa' [blank slate] when commencing the research (Clarke, 2005; Glaser, 2003; Locke, 2001). In contrast, Charmaz (2014) advises that the researcher would need to give consideration to the research question, encouraging an early exploration of the literature. I remain cognisant of the inherent tensions in commencing the narrative review too early. However, it is acknowledged that a comprehensive narrative synthesis of previously published data will help in identification of themes in the literature and 'gaps' in the knowledge base (Green *et al*, 2006; Marshall, 2005).

Fundamentally, the narrative review will determine if existing empirical evidence can contribute anything to the research proposal or whether further study is indicated (Ferrari, 2015). Reviewing previously published literature is an essential element of the research process, known as the literature review (Coughlan *et al*, 2013; Bernard and Ryan, 2010).

Critical appraisal of the literature is a structured process to determine the merits or value of

the research (Moule and Goodman, 2014). Analytical and critical appraisal of the evidence, using the structured tool known as IMRAD (Introduction, Methods, Results and Discussion), allows new research ideas to flourish (Grbich, 2003; Ferrari, 2015). Critical reading of the literature can be described as follows:

"An active process concerned with learning to think, and hence read; that means using mental processes such as attention, categorisation, selection and judgement"

(Cottrell 2011; p 119).

Furthermore, Rumrill *et al*, (2010) describe a five step approach when conducting a narrative literature review including; identification of the research area, identification of inclusion criteria for studies, selecting studies that meet the inclusion criteria, identification of themes that emerge from the set of studies, and draw conclusions. Rumrill *et al*, (2010) suggest that a narrative review of the literature presents an opportunity to *"reshape previously existing information in a way that contributes new perspectives"* and that:

"Narrative literature reviews contribute to the research and practice of their specific fields by creating greater depth and insight than can be gleaned from an individual study"

(p 400).

Therefore, the advantage of conducting a narrative review of the literature is that it summarises different primary studies from which conclusions can be drawn into a holistic interpretation. In turn, the literature review process is enriched by the researcher's own experiences, interpretations, existing theories and philosophical perspectives (Charmaz, 2006; Jones, 2004).

Consistent with the epistemological views and ontological assumptions outlined in Chapter 1, the narrative review is an opportunity to engage with literature about the social interactions of critical care staff. Dey (1999) suggests that the literature review supports the generation of

research questions, essentially when exploring human interaction (critical care staff) with a defined phenomenon (organ donation). Glaser (1992) insists that the researcher should ideally enter the research project with no preconceived problem statement, interview protocol or extensive review of the literature. However, I assert that Glaser's view is problematic to the novice grounded theorist as the narrative review, specifically when it is conducted, is an ongoing contentious issue. Chapter 1 outlined my previous professional experiences as a nurse, including 8 years as a specialist nurse – organ donation. I argue it is challenging to decouple my professional background in organ donation and that "*an open mind does not imply an empty head*" (Timmermans and Tavory, 2012: p 170). These reflections dovetail the views of Charmaz (2006; 2014) and Clarke (2005) that the problem with classical grounded theory is the pretence that the researcher should be invisible during the research process:

"I assert that we cannot help but come to almost any research project already knowing in some ways, already inflected, already affected, already infected"

(Clarke, 2005; p 12).

Furthermore, a narrative review of the literature supports the shaping of ideas regarding the selection of an appropriate methodology for the study. Exploring the methodological frameworks used in previous studies will provide insight into different approaches to research (Richards, 2015).

2.3 Search Strategy

This section explains how the narrative review was conducted and the framework used to source, refine and critique evidence. To summarise, a narrative review can be defined as a method of rapidly identifying the key concepts that underpin the research and the type of evidence available (Ferrari, 2015). The purpose of the narrative review was to identify as

many relevant primary sources of evidence as possible relating to critical care staff experiences of approaching relatives for organ donation following the death of a patient. This includes accessing electronic databases and searching professional organisational websites. The search date was restricted to the previous ten years (2008 – 2017), ensuring capture of contemporary literature. However, it was apparent that seminal pieces of literature preceded the ten year restriction. On this basis, the time frame to include studies from the year 2000 onwards. For example, a study by White (2003) explored ICU nurses perception of brain death which was considered relevant to the study.

The initial search strategy generated many unwanted and irrelevant evidence. Due to the difficulty in translating papers, only articles written in English were reviewed. The structured framework offered by Ferrari (2015) encouraged the development of an inclusion and exclusion criteria. This was helpful in focusing on the relevance of the studies to the research topic. Additionally, the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) were used to help select and refine evidence based on a minimum set of items using a 27 item checklist and four phase flow diagram (Figure 1) (Moher *et al*, 2009; Appendix 1). The following inclusion and exclusion was applied following a systematic search of journal databases (Table 2.1).

Table 2.1: Inclusion / Exclusion Criteria

Inclusion	Exclusion
<ol style="list-style-type: none"> 1. Study taken place in critical care setting (ICU / ED) 2. Study published from year 2000 onwards 3. Full text available 4. Written in English 5. Study had to relate to critical care staff experiences / attitudes / perceptions 	<ol style="list-style-type: none"> 1. Papers that focused on purely death / dying and not related to organ donation 2. Papers that focused on donor optimisation / donor management 3. Papers that discussed biomedical disorders relating to brainstem death

The search strategy included access to three online databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Online (Medline) (Ovid) and British Nursing Index (Table 2.2). These three databases are reported to be the most useful for nursing research (Birks and Mills, 2015; Richards, 2015). Additionally, I explored professional websites for further evidence related to the research topic.

A series of synonyms was constructed using a combination of truncations and quotations to best capture the search term. Using Boolean search operators, the search was further refined with limits placed on studies from 2000 – 2017 (example screenshots of the database search are located in Appendix 2). The following search words were used: '*organ donation*', '*organ transplant*', '*organ donor*' '*critical care*', '*intensive care*', '*emergency department*', '*experience*', '*attitude*', '*belief*', '*opinion*', '*death*', '*dying*' and '*end of life care*'.

The search term '*organ donation*' generated a total of 1,892 articles on CINAHL, 338 on British Nursing Index and 7545 on Medline, suggestive of an area of consistent research. Refinement of search terms to include '*organ donation*' AND '*intensive care*' AND '*experiences*' AND '*death*', generated a total of 95 research articles on CINAHL, 44 on British Nursing Index search and 362 on Medline (Figure 2.1).

Following further refinement based on duplication, those articles not written in English and year of publication restriction of 2000 - 2017 (see Figure 2.1), a total of (**n = 26**) articles were included for the final critique. Interestingly, many of the articles explored nurses' attitude in survey format and a total of (N = 0) research articles could be identified that specifically explored critical care staff experiences of organ donation following the death of a patient. Figure 2.1 depicts the flow chart of the literature selection process for the research question. The initial search of the databases occurred during 2015-2016 but the search strategy was repeated during October 2017 to capture recent studies.

Table 2.2: List of databases used in search strategy

Database	Database description
British Nursing Index	British Nursing Index is a leading database for support of practice, education, and research for nurses, midwives, and health providers in the UK or following UK practice. It provides references to literature in the most relevant nursing and midwifery journals.
CINAHL (Cumulative Index to Nursing and Allied Health Literature)	The largest, most in-depth database contains 3,800,000 records. Offering complete coverage of English language nursing journals, publications from the Journal of Advanced Nursing and the British Journal of Nursing, CINAHL covers nursing, biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and 17 allied health disciplines.
Medline	MEDLINE (Medical Literature Analysis and Retrieval System Online, or MEDLARS Online) is a bibliographic database of life sciences and biomedical information. It includes bibliographic information for articles from academic journals covering medicine, nursing, pharmacy, dentistry, veterinary medicine, and health care.

2.4 Search Results

The overlap of the database searches produced duplicate papers which were removed from the results. Following application of the refined search criterion and use of the screening tool as advised by Ferrari (2015), a total of twenty six articles (Table 2.2) are contained within the results of the narrative review. The final table of results is presented in tabular form and critiqued using the IMRAD (Introduction, Methods, Results, Discussion) protocol. I contend that tabulation of the literature assisted me in the identification of themes and connections in the literature, consistent with the iterative process of the study (Table 2.3).

Figure 2.1: PRISMA flow chart of the literature selection process

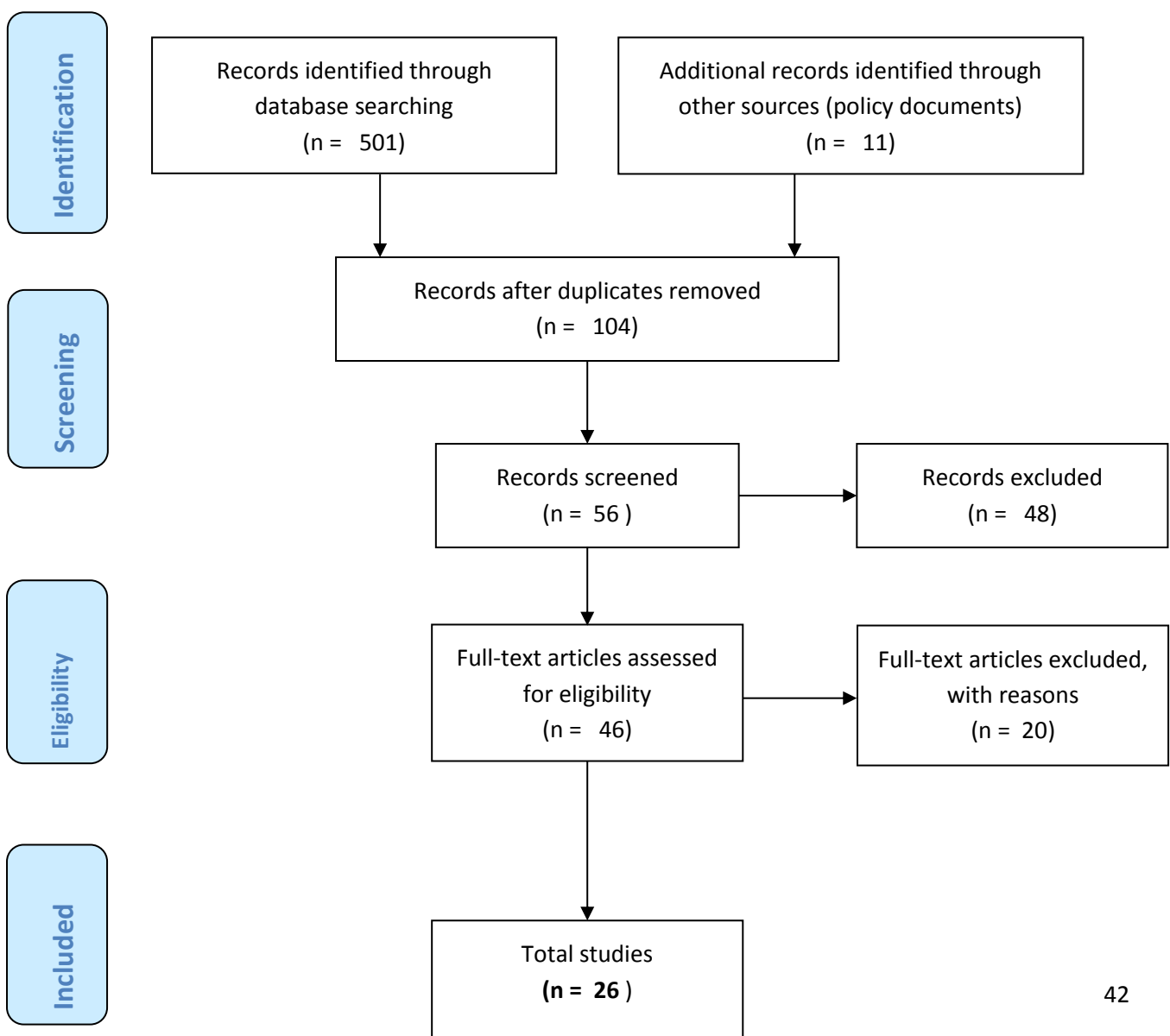


Table 2.3: Results of the final articles following the systematic search of the databases

Author and Country	Introduction	Methods	Results	Discussion
IMRAD (Introduction, Methods, Results and Discussion) – Ferrari (2015)				
Lomero M, Jiménez-Herrera M, Rasero M, and Sandiumenge A, (2017) – Spain	The study was conducted to explore whether nurses attitudes and knowledge towards organ donation influences decisions to donate.	Survey using 35 item questionnaires. Three separate hospital sites covering a total of 7 ICU's. 214 questionnaires were distributed with a response rate of 68.2%.	Results were subjected to descriptive and comparative statistical analysis. 72.2% agreed brain death is equivalent to death.	29.6% (nearly a third) of nurses were unsure or disagreed if brain death is equivalent to death. 86.7% of nurses reported they would like further training on organ donation and transplantation. Permanent night staff and those staff with no religious views were more likely to allow organ donation from their relative.

<p>Department of Health (2008)- Organs for Transplant Report - UK</p>	<p>Report from the Organ Donation Taskforce</p>	<p>Aim to increase organ donation by 50% over a five year period following implementation of 14 recommendations.</p>	<p>Strategic changes to organ donation and transplant services. Radical overhaul of education and training in donor hospitals.</p>	<p>Implementation of 14 recommendations to change practice. UK-Network of Specialist Nurses – Organ Donation (SNOD) and Clinical Leads for Organ Donation (CLOD). Construction of Organ Donation Committees in donor hospitals. Meticulous scrutiny of donation and transplant activity in each donor hospitals. Action plan to encourage BAME donation.</p>
<p>Aud Orøy, Kjell Erik Strómskag and Eva Gjengedal (2015) - Norway</p>	<p>The objective of this study was to examine health care professionals experience of ethics related to care and</p>	<p>2 ICU’s and a total of 12 cases observed. Data collection consisted of participant observation and in-depth interviews</p>	<p>Following thematic analysis, interaction with families was characterized by ambiguity and</p>	<p>The prognostic process had greatest impact on the family. Additionally, the study captured the importance of ICU staff experience. Norwegian study but findings may provide common</p>

	interaction with critically ill patients with severe brain injuries and their families		withholding information	insight into ethical challenges of caring for patients in complex situations
Stéphanie Camut, Antoine Baumann, Véronique Dubois, Xavier Ducrocq and Gérard Audibert (2016) - France	Providing non-therapeutic intensive care (NTIC) for hopeless condition after cerebrovascular stroke – an exploratory study to scope feelings and opinions.	340 health care professionals targeted, only 51% returning filled in form	Suboptimal education regarding brain death was identified. 75% of respondents thought NTIC was a continuation of the patients care.	Single centre opinion survey

<p>G Citerio, M Cypel, G Dobb, G Dominguez- Gil, JA Frontera, D Greer, AR Manara, SD Shemie, M Smith, F Valenza and EF Wijdicks (2016) - Europe</p>	<p>A European review of the potential for organ donation in adult ICU following plans to remove ICU treatment.</p>	<p>Review of deceased organ donation pathways in Europe</p>	<p>Strategies to increase the number of donor organs is discussed: timely identification of donors, implementation of DCD protocol.</p>	<p>ICU staff are identified as key professionals in the organ donation process.</p>
<p>Vijayalakshmi P, Nagarajaiah, Ramachandra, Bada Math S, (2015) – India</p>	<p>Study aim was to investigate nurses' attitude towards organ donation.</p>	<p>A cross-sectional descriptive survey was carried out amongst nurses (n=184). Data was collected by self report questionnaire.</p>	<p>The study detected a significant correlation between intention to sign the organ donor card, gender and experiences in caring for brain-dead patients.</p>	<p>The researchers strongly suggest that education is needed to enhance nursing skill and knowledge regarding organ donation.</p>

<p>LM Lin, Chiu Lin, C Chen and Chih Lin (2014) - Taiwan</p>	<p>To explore the effects of an education program based on the Theory planned Behaviour (TPB) on ICU nurses' attitudes and behavioral intentions to advocate deceased organ donation.</p>	<p>Sample from 3 different ICU's, 61 in experimental group and 62 in control group</p>	<p>After TPB training, nurses in the experimental group significantly changed their attitudes, both immediately ($P < .01$) and two months after ($P < .05$).</p>	<p>Education program not explored in detail – who facilitated? Time / duration of each session and how were the groups split.</p>
<p>Helene Berntzen and Ida Torunn Bjørk (2014) - Norway</p>	<p>The study was designed to investigate the experience of Norwegian donor families during organ donation after brain death.</p>	<p>20 donor families from 13 different case scenarios were interviewed about experiences of organ donation from their relative following brain death.</p>	<p>Lack of awareness contributed to an experience of 'strain' caused by the organ donation process on relatives.</p>	<p>Healthcare professionals were identified as key personnel in understanding, recognising the potential for organ donation and initiating discussions with potential donor families.</p>

<p>Una St Ledger, Ann Begley, Joanne Reid, Lindsay Prior, Danny McAuley and Bronagh Blackwood (2013) - UK</p>	<p>The study explores the moral distress in relatives, doctors and nurses in end of life care decision-making in the adult intensive care unit.</p>	<p>A narrative inquiry case study approach, in depth recorded interviews with relatives, doctors and nurses involved in end of life cases.</p>	<p>Research protocol, study template only.</p>	<p>Purposive sample of 2 relatives and 2 health care professionals. Provides evidence that anxiety in the donation discussion is the focus of intended research.</p>
<p>Shayesteh Salehi, Tahereh Kanani and Heidarali Abedi (2013) – Iran</p>	<p>The study describes the nurses' experiences of care of brain dead donors in intensive care units (ICU)</p>	<p>Adopted a phenomenological method, purposive sample used to gather data. 8 participants from ICU nurses who had cared for brain dead donors.</p>	<p>Analysis led to main theme of “excruciating tasks”, heavy and stressful care and deficit in knowledge</p>	<p>Iranian study, Muslim faith. The study states that post-traumatic stress provision may be prudent, some nurses reporting high levels of stress and apprehension</p>

<p>Lee Polikoff and Megan McCabe (2013) - USA</p>	<p>Review of the literature relating to end of life care in the pediatric ICU</p>	<p>Literature review</p>	<p>PICU practitioners are developing flexible and novel approaches to pediatric end of life care in the ICU setting</p>	<p>Not original research but highlights the anxiety associated with end of life care decisions. Organ donation is not mentioned.</p>
<p>Maureen Coombes, Julia Addington-Hall, Tracy Long-Sutehall (2012) - UK</p>	<p>To identify the challenges for health care professionals when moving from a recovery trajectory to an end of life trajectory in intensive care.</p>	<p>Single semi-structured interviews with 13 medical staff and 13 nurses associated with 17 decedents who underwent treatment withdrawal in intensive care were carried out.</p>	<p>Patients who died in intensive care appeared to follow a three-stage end of life trajectory: admission with hope of recovery; transition from intervention to end of life care; a controlled death.</p>	<p>Emphasises need to focus on transition from curative to end of life care. The study highlighted the inherent tensions experienced by critical care professionals when care trajectory moves towards end of life care (EoLC).</p>

<p>Käthe Meyer, Ida Torunn Bjørk and Hilde Eide (2011) - Norway</p>	<p>The paper examines Norwegian ICU nurses perceptions of their professional competence relating to organ donation.</p>	<p>A cross-sectional survey was conducted in 28 donor hospitals. A total of 801 nurses were invited to take part, 71.4% response rate.</p>	<p>Few ICU nurses had experience and competence or training in organ donation. Nurses working in University affiliated hospitals had more experience.</p>	<p>Training provided by experienced colleagues can help develop professional competence. However, this was not measured and requires further investigation.</p>
<p>Anne Flodèn, Lars-Olof Persson, Magnus Rizell, Margareta Sanner and Anna Forsberg (2011) - Sweden</p>	<p>Explores Swedish ICU nurses attitudes to brain death and organ donation.</p>	<p>A 34 item instrument was developed to explore attitudes and experiences of organ donation.</p>	<p>A questionnaire was sent to 50% of ICU nurses in Sweden (n = 1013), response rate was 69%. Chi squared test used to compare responses.</p>	<p>39% of respondents reported occasions when organ donation was never raised / discussed with relatives. Personal attitudes amongst staff were discussed.</p>

<p>Julien Garside, Marie Garside, Simon Fletcher, Bruce Finlayson (2011) – UK</p>	<p>To review the impact of a specialist nurse – organ donation on organ donation in the emergency department over a 24 month period.</p>	<p>A retrospective cohort study of adult deaths in the emergency department on referral to organ donation team prior to implementing a SNOD and collaborative care pathway.</p>	<p>The number of patients proceeding to organ donation increased from none to two (Fisher’s exact test p¹/41.0).</p>	<p>The presence of an embedded Specialist Nurse Organ Donation (SNOD) in the ED and the adoption of a collaborative care pathway to establish clinical triggers for referral to the ODT have significantly increased the rate of referral of adult potential organ donors to organ donation services.</p>
<p>A Zampieron and AC Frigo (2010) - Italy</p>	<p>To examine undergraduate nursing students’ attitudes towards organ donation.</p>	<p>378 students contacted.</p>	<p>Only 16 % students had previously signed a donor card, no correlation exists between organ donation and age, sex and clinical practice.</p>	<p>Organ donation insight was lower than in other countries. This study suggests international variation in personal uptake / support for organ donation amongst student nurses / medical students.</p>

<p>CV Brown, KH Foulkrod, S Dworaczyk, K Thompson, E Elliot, H Cooper and B Coopwood (2010) - UK</p>	<p>The purpose of this study was to compare families who declined organ donation to those who granted consent, specifically to identify barriers to family consent for successful organ donation.</p>	<p>Variables collected included age, gender, race, cause of brain death (trauma vs. medical) of the potential organ donor, and elapsed time from declaration of brain death to family approach by OPO.</p>	<p>Several barriers exist to family consent for successful organ donation. Family members of minority populations, medical brain deaths, and older potential donors more often decline consent for organ donation.</p>	<p>Family education and resource utilization toward these specific populations of potential organ donors may help to improve organ donation consent rates. Relative / carer consideration.</p>
<p>Seale (2009) - UK</p>	<p>To investigate the prevalence of end of life care decisions which doctors expect or at least partly intend to hasten death.</p>	<p>National survey of 3733 doctors – mixed disciplines.</p>	<p>Intensive care physicians were particularly likely to report a degree of intention to hasten end of life and to have treated patients lacking capacity.</p>	<p>Doctors with strong religious conviction have greatest concern in decisions that hasten end of life.</p>

<p>Mari Lloyd-Williams, Juliet Morton and Sarah Peters (2009) - UK</p>	<p>Qualitative study carried out with relatives of patients who had died of brain death in an ICU.</p>	<p>20 ICU's recruited for the study, 30 relatives agreed to take part.</p>	<p>Participants valued physical care of their relative but reported poor communication and breaking bad news as a cause for concern.</p>	<p>Participants reported cramped waiting rooms and lack of privacy. Education and training a key feature in positive donation outcome. The study highlighted the challenges with recruitment of participants – 20 ICU's recruited, research team but only 30 relatives (out of 120 identified and approached) agreed to be involved in the study.</p>
<p>Magi Sque, Tracy Long, Sheila Payne and Diana Allardyce (2007) – UK</p>	<p>A study that explored the reasons family members declined organ donation from a deceased relative.</p>	<p>A convenience sample of 26 family members who declined organ donation, recruited by three media campaigns.</p>	<p>Donation decisions hinged on many converging factors – relatives reported need to protect the dead body.</p>	<p>Pro-donation views of the family, or the deceased in life, did not guarantee organ donation. Relative / carer considerations.</p>

<p>Jung Ran Kim, Murray John Fisher, Doug Elliott (2006) – Australia</p>	<p>Reports the development and testing of an instrument assessing attitudes of Korean intensive care nurses.</p>	<p>A 38 instrument was developed. A survey was conducted with Korean ICU nurses (N=520).</p>	<p>Suggestive of high internal consistency (alpha = 0.88). Principal finding was discomfort in organ donation and disbelief in brain death.</p>	<p>Similar to study by Cantwell and Clifford (2000), Collins (2005). This study highlights the uncertainty and discomfort attributed to the testing and diagnosis of brainstem death.</p>
<p>FA Muthny, S Wiedebusch, GA Blok and J van Dalen (2006) - Germany</p>	<p>Evaluation of 1 day workshop adapted from the European Donor Hospital education Programme (EDHEP).</p>	<p>Evaluation of 75 German organ donation workshops and experiences of 760 participants.</p>	<p>Two thirds of respondents reported that the workshop assisted with difficult donation discussions and that relatives could be helped with the training.</p>	<p>Education and Training important components in successful organ donation outcomes.</p>

<p>Deborah Cook, Graeme rocker, John Marshall, Peter Sjokvist, Peter Dodek, Lauren Griffith, Andreas Freitag, Joseph Varon, Christine Bradley, Mitchell Levy, Simon Finfer, Cindy Hamielec, Stephen Walter and Gordon Guyatt (2006) – USA</p>	<p>Study of adults who were receiving mechanical ventilation and the withdrawal of mechanical ventilation in anticipation of death in the intensive care unit.</p>	<p>15 intensive care units recruited. Study included 851 patients experiencing multi organ failure, patient’s capacity to make decision, type of life support and type of do not resuscitate order. Use of Cox proportional-hazards regression analysis to explore clinicians’ prediction of futility and clinical determinants associated with withdrawal of life-sustaining treatment (WLST).</p>	<p>63.3% were successfully weaned, 17.2 % patients died whilst still being mechanically ventilated, 19.5% had mechanical ventilation withdrawn.</p>	<p>Allows scoping of the potential for DCD donation. Despite the potential for DCD donation, the study highlights that critical care staff have a number of ethical, moral and professional concerns with this particular mode of donation.</p> <p>Rather than age or severity of illness, findings suggest the strongest determinant for WLST was clinicians’ perception that the patient preferred not to use life support, combined with low likelihood of survival and poor cognitive function.</p>
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<p>Geoff White (2003) – Australia</p>	<p>Explored ICU nurses perception of brain death as a meaningful concept of death.</p>	<p>Sample of 40 ICU nurses included in the study. Utilised semi-structured interviews to extract data.</p>	<p>Study revealed five categories ranging from complete acceptance to complete rejection.</p>	<p>Study confirms that a high proportion of the sample (48%, n=19) regarded a brain dead patient as less than completely meaningfully dead. Generally, the participants were well informed practitioners but held dissonant perceptions about the nature of brain death.</p>
<p>Rebecca Stroud (2002) - UK</p>	<p>Discussion paper on the withdrawal of life support in adult intensive care.</p>		<p>Literature demonstrates that the decision to withdraw life sustaining treatment is a common and increasing practice.</p>	<p>Reinforces that ICU nurses find this subject challenging. Death / dying.</p>

<p>Michelle Cantwell and Colette Clifford (2000) - UK</p>	<p>To examine nursing and medical students' attitudes towards organ and corneal donation.</p>	<p>Sample of 72 nursing and medical students completed a 61 item quantitative questionnaire.</p>	<p>74% of nurses had already signed donor card, compared to only 43% medical students – significant P value between two groups (P=0.005).</p>	<p>Single site, doubt about organ donation exists within medical student group. 74% of nursing students had signed donor cards, compared to 43% of medical students. Conclusion was that further study was needed to explore this phenomenon.</p>
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2.5 The Narrative Overview

Following the selection of the final twenty-six articles for critique (eleven qualitative, twelve quantitative and three policy documents), an iterative process was used to identify links and connections within the evidence sources. I have argued that the analytical process was made easier by the tabular collation of the search strategy results (Table 2). The final stage of the narrative review provides a narrative overview of the selected articles. Charmaz (2007) recommends identifying links within the data set and the iterative process of the grounded theory study explicated six broad categories within the evidence sources including: ‘Education and training’, ‘policy and protocol’, ‘critical care staff experiences of organ donation’, ‘relative / carer experiences’, ‘the organ donation request’ and ‘transition to end of life care’. As argued by Ferrari (2015) and Green *et al*, (2006), drafting the narrative overview text rarely follows a linear pathway but the collating of results into themes helps with identification of gaps in the literature.

2.5.1 Theme 1: Education and Training

A common theme following the narrative review focused on the education and training of critical care professionals relating to organ donation. For example, Camut *et al*, (2016); Vijayalakshmi *et al*, (2015); Lin *et al*, (2014); Salehi *et al*, (2013); Meyer *et al*, (2012); Muthny *et al*, (2006); Jacoby *et al*, (2005) assert that training needs and various training courses have influenced critical care staff experiences of organ donation. Interestingly, education and training education of ICU staff relating to organ donation appears to be a prominent feature of research.

Writers in both academic and professional journals discuss the importance of education and training to achieve competence within professional roles. For example, Meyer *et al*, (2012) who conducted a large cross sectional survey of 28 Intensive Care Units (ICU). The intention of the study by Meyer *et al*, (2012) was to explore the professional competence of ICU nurses' educational needs in the donation process. A total of 801 ICU nurses were invited to take part in the study with an encouraging response rate of 71.4%.

Meyer *et al's*, (2012) survey consisted of twenty-two items which explored the professional competence in the theoretical and practical components of the donation process. This study highlights the link with the importance of an educated workforce on all aspects of the organ donation process. Findings from this study suggest that nurses working in a university affiliated hospital are more likely to participate in making the request for organ donation. Nurses acknowledged that exposure to hospital based education influenced their professional competence in the donation process. However, the findings may not be transferable because the study was conducted in Norway which has a part public, part private healthcare system and did not include the professional competence of ICU doctors. Exploring the experiences of all critical care staff would develop a better understanding of what influences their readiness to engage in organ donation following end of life decisions. The study findings report that formal education of ICU staff is a crucial component in ensuring professional competence in the donation process.

A similar method was used by Lomero *et al*, (2017) who conducted a survey of nurses' attitudes and knowledge regarding organ and tissue donation. The sample sites included seven ICU's across three separate centres in Barcelona, Spain. A total of 214 questionnaires were distributed with a response rate of 68.2%. Interestingly, the study concluded that 29.6% of nursing staff were unsure or disagreed that brain death is equivalent to death. In addition, 86.7% of respondents expressed an interest in further education and training relating to organ

donation and transplantation. This study highlights that some critical care professionals are not confident that brainstem death equates to death.

In contrast, education and training was not popular with all authors and some, such as Jacoby *et al*, (2005), have undertaken work to refute the significance. Jacoby *et al*, (2005) explored the impact of an uneducated workforce related to organ donation. In addition, Jacoby *et al*, (2005) claimed that a simulated training method in empathic communication provided better knowledge and skills for staff to support potential donor families, however this was not tested. The study also acknowledged this was a single site study which would need adapting and testing for larger audiences. Jacoby *et al*, (2005) contest that education and training does not provide all the solutions but assert that effective communication is critical when caring for a potential organ donor and their relative.

Education and training is considered to be a great influence on critical care professional's engagement with organ donation. For example, Muthny *et al*, (2006) explored the impact of a European Donor Hospital Education Programme (EDHEP) for doctors and nurses who deal with sudden death. The EDHEP training initiative is significant because it has been implemented in over thirty countries worldwide and translated into seventeen languages. Muthny *et al*, (2006) evaluated the impact of the EDHEP in Germany following the initial training programme in Holland. The aim of the EDHEP was intended to allow doctors and nurses to learn about the psychology of reactions to loss and grief and to enhance the delivery of bad news. The workshop adopted different working methods including self-experience to reflect personal experience with sudden death, video and case vignettes.

The study by Muthny *et al*, (2006) evaluated the effects of seventy-five one-day EDHEP workshops and experiences of 760 participants (doctors, nurses and psychologists). One third of participants requested to run workshops over two days, suggesting a training need in the

area of grief / bereavement response and donation discussions. Two thirds of participants reported that relatives could be helped, talked with, and cared for in a better way. In summary, the evaluation conducted by Muthny *et al*, (2006) indicates that there is a critical need for additional psychosocial training in the diagnosis of brain and cardiac death. This validates the findings from the studies by Meyer *et al*, (2012) which indicates that a causal link could exist between staff training and positive donation outcomes.

Drawing on the work by Muthny *et al*, (2006), Camut *et al*, (2016) conducted a single-centre opinion survey of staff attitudes towards organ donation in a large French University Hospital. The aim of the study was to explore the feelings and acceptance by healthcare professionals of Non-Therapeutic Intensive Care (NTIC) for brain death organ donation and to assess their training needs. A questionnaire with 13 multiple choice questions and one open-ended question was distributed to staff working in neurosurgical, surgical, medical and intensive care wards. Of the total 340 health care professionals who expressed interest, 51% filled in the questionnaire. The findings report that 21.8% of the staff had received formal education on brain death, and only 18% on the needs of the family during donation discussions.

The findings by Camut *et al*, (2016) suggest that the acceptance of Non-Therapeutic Intensive Care (NITC) as a method to increase organ donation is widely accepted by health care professionals. However, a small number (n = 16%) of respondents stated that they had received specific training on NITC and 5% of respondents viewed NITC as shocking or degrading. If only a small percentage had received formal training on NITC, it appears the majority had formulated their decisions regarding NITC on limited information and knowledge.

An identified weakness of the study by Camut *et al*, (2016) is that it is a single-centre endeavour with only 51% of the targeted health care professionals responding to the survey. Moule and Goodman (2014) state that a response rate of 75% and above is generally regarded as good, this study falling well below this identified response rate. Of the 51% who did respond, it is feasible that the remaining 49% may differ in some significant way to other responders.

The narrative review revealed that stress and anxiety were common themes explored within the education and training provision for critical care staff. A study by Salehi *et al*, (2013) reported high levels of stress amongst nurses caring for brain dead donors. Employing a purposive sample to collect data, a series of eight in depth interviews were conducted with ICU nurses who had cared for people who were brain dead donors. Following analysis of the data, the main theme identified was that ICU nurses described caring for brain dead donors [sic] as an “excruciating task”. However, this study was conducted in Iran, organ donation being a new phenomenon in this country. The study did not explore the interactions between the ICU nurses and relatives, but focused on the experiences of caring for the brain dead donor. I suggest that further work was needed to determine whether a causal link exists between education and training and high levels of stress amongst nurses. In a similar way, White (2003) reported that 48% (n=19) of nurses in a study of ICU nurses’ perception of brain death regarded a brain stem dead patient as less than completely meaningfully dead.

A further study by Lin *et al*, (2014) investigated the effects of an education program on ICU nurses’ attitudes and behavioural intentions to advocate deceased donor organ donation. The purpose of Lin *et al*’s research study was to explore the effects of an education programme based on the Theory and Planned Behaviour (TPB) on ICU nurses’ attitudes and behavioural intentions to advocate deceased organ donation. Nurses were recruited from three different ICU units in medical centres and subsequently randomly assigned to an experimental group

(n = 61) or a control group (n= 62). The nurses allocated to the experimental group received comprehensive education programs, and the control group received only basic literature. Lin *et al*, (2012) assert there was no difference in attitude and behaviour intentions between groups prior to the study but fail to stipulate how this was measured.

Results from the study by Lin *et al*, (2014) clearly demonstrate that nurses changed their attitudes and intention in organ advocating, both immediately, and two months after the education program. The TPB strategy appears to directly and positively influence nurses' attitudes and intentions on organ advocacy. However, inspection of the intervention used (TPB) fails to clearly identify how the training to the experimental group was delivered. Activities such as viewing videos of organ donation promotion, sharing of recipient stories / experiences and journey of the donor family all feature within the teaching strategy. In conclusion, a detailed explanation in how the groups were split, who delivered the training and the duration of the teaching sessions would add further credence to the study.

To summarise, education and training of ICU staff in the organ donation process appears to be an important topic. Having explored a number of research articles, the research indicates that education and training does not provide all the solutions for barriers to organ donation.

2.5.2 Theme 2: Policy and Protocol

In the UK, it is promoted that nurses work in an evidence based culture to ensure optimal nursing care (The Code, NMC 2015; NICE, 2011). The narrative review of the literature identified a number of papers which explored the significance of policy and protocol relating to organ donation. For example, Citerio *et al* (2016) explored the potential for deceased organ donation in adult ICU practice, focusing on donation after brain death (DBD), and controlled

Donation after Circulatory Death (DCD), the form of donation that follows withdrawal of life sustaining treatment (WLST). This international research established that 70% of nations have a legal framework surrounding the diagnosis of brain stem death, though protocols are less common in low income countries like Moldova and Armenia. In addition, Citerio *et al*, (2016) state that only 75 countries (38% of the world's countries) have deceased donor programs.

The results from the Citerio *et al*, (2016) study affirm that operational policy is critical in the ICU to increase the number of donated organs. This includes policies for the timely identification of a potential organ donor, optimization of the brain dead donor [sic] to enhance organ viability and implementation of new technologies to improve the donor pool (Bleakley, 2010). Nevertheless, this international review of organ donation in adult ICU does not discuss the training needs of critical care practitioners. The paper by Citerio *et al*, (2016) focuses on the importance of implementing protocols to improve the number of donated organs but fails to adequately investigate the human interaction of the critical care team with potential donor families.

In comparison to the protocol developed by Citerio *et al*, (2016), Garside *et al*, (2011) conducted a retrospective cohort study exploring utilisation of an embedded specialist nurse and collaborative care pathway to determine increases in potential organ donor referrals in the emergency department. The objective of the study by Garside *et al*, (2016) was to review the impact of an embedded specialist nurse in organ donation (SNOD) and the utilisation of a collaborative care pathway on potential solid organ donor referrals in an emergency department (ED) over a two year period.

A retrospective cohort study was conducted by Garside *et al*, (2011), incorporating adult patient deaths within the department, (n = 311) during a 24-month period. Referral rates to

the organ donation team (ODT) were compared before and after the introduction of a SNOD and collaborative care pathway. In conclusion, the study states that the presence of an embedded SNOD in the ED and the adoption of a collaborative care pathway to establish clinical triggers for referral to the ODT have significantly increased the rate of referral of adult potential organ donors to organ donation services. This research suggests the SNOD, combined with the critical care team, achieve higher referral rates, meaning the potential for missed referral is reduced. Furthermore, exploring how the critical care team interact with the SNOD team is an important aspect of the proposed research.

In 2008, the *Organs for Transplant Report* (DoH, 2008) was published and stipulated that fourteen recommendations were needed to radically overhaul organ donation in the UK. The report highlighted that education of key stakeholders, including ICU professionals, was a major component of the organ donation taskforce (ODTF) recommendations:

In particular, recommendation 11 states that:

“All clinical staff likely to be involved in the treatment of potential donors should receive mandatory training in the principles of donation. There should also be regular update training”

(DoH, 2008: p 47).

This recommendation highlights that education and training of staff has been a major consideration in the development of operational policy concerning organ donation.

Furthermore, the *Organs for Transplant Report* (2008) has, arguably, transformed education and training regarding organ donation in the UK. This is significant as many changes, including the implementation of minimum notification criteria for organ donation and a Specialist Nurse – Organ Donation (SNOD) being assigned to every acute hospital in the UK, was a direct result of this report (Bleakley, 2010; DoH, 2008). These changes could only be achieved by ensuring an educated workforce through implementation of all 14

recommendations (DoH, 2008). Despite this national policy being implemented into UK-wide acute hospitals, it isn't mandatory for critical care staff to engage with education and training related to organ donation. In conclusion, the implementation of policies and protocol to support organ donation within critical care appears to impact positively on donor rates. However, as suggested in the previous section, such policies do not account for human fear and anxiety associated with challenging donation conversations.

2.5.3 Theme 3: Critical care staff experiences of organ donation

The third theme to emerge from the narrative review relates to the professional experiences of critical care staff regarding organ donation. Flodén *et al* (2011) conducted a similar study to Meyer *et al* (2012) and explored the attitudes to organ donation among ICU nurses. The study suggests that a significant barrier to organ transplantation is critical care staff attitude. A questionnaire was posted to 50% of total ICU nurses in Sweden (N = 1013) with a response rate of 69% which represents 702 staff. Chi-squared tests and a Pearson correlation test were employed to explore the relationship between specified factors of staff attitude to organ donation.

The study conducted by Flodén *et al* revealed that a total of 39% of ICU nurses had experienced situations when organ donation was never discussed with the family (organ donation was a possibility in all reported cases). A disadvantage in the use of questionnaires is that it provides limited information about the context in which respondents formulate their responses (Parahoo, 2006) and the researcher is unable to ask the respondent to elaborate on answers provided. Semi-structured interviews with the ICU nurses may have enhanced this study further, allowing a richer understanding of personal experiences and actions. A grounded theory study is dependent on the ability of the researcher to navigate the interview

path with the participant. Imposing too much structure to the interview is restrictive and prevents the researcher “following where conversations take you” (Birks and Mills, 2015; p 73). In conclusion, the study by Flodén *et al* (2011) reinforced the importance of formal educational initiatives to support ICU staff in the organ donation process thus preventing the phenomena of organ donation being omitted in end of life care conversations.

Critical care staff attitudes were a prominent focus within the narrative review and this appears to be a significant influence on nursing practice. Similarly, Collins (2005) explored nurse’s attitudes towards organ donation in the UK through a survey of 31 registered ICU nurses and discovered that nurses have a range of negative and positive beliefs. The results from the survey by Collins (2005) revealed that 5% of the nurses ‘disagreed’ with organ donation and a further 10% of nurses went further and ‘strongly disagreed’ with organ donation. However, Collins’ (2005) study was on a smaller scale to that of Flodén, a total of (N = 31) were nurses assessed through questionnaire on their beliefs about diagnosis of death and organ donation. Interestingly, Collins (2005) demonstrated that only 45% (n = 14) stated in their responses that they were fully aware of the legal requirements of the criteria for brain stem death testing. Similar findings were reported in the study by Meyer *et al* (2011). This rather startling statistic suggests that despite the implementation of educational policy to enhance donation knowledge (NICE, 2011; DoH, 2008), some critical care staff still practice with inadequate levels of knowledge on the legal requirements for brainstem death testing.

Attitudes and experiences of organ donation have been measured in various studies (Zampieron *et al*, 2010, Cantwell and Clifford, 2000). Findings generally report relatively good support and positive attitude by qualified nurses. For example, Zampieron *et al* (2010) asked 378 student nurses to complete a self-administered quantitative questionnaire comprised of 61 questions, assessing attitude towards organ donation. The study by

Zampieron *et al*, (2010) indicates an overall negative attitude score towards organ donation (n = 151), the attitude is positive when the score is higher than 161.

Likewise, attitudes of intensive care nurses towards brain death and organ transplantation has been examined by Kim *et al*, (2006), who reported that 89% of respondents did not have any experience of attending any education related to brain death and organ transplantation. The study reveals that the shortfall in the number of organ donors internationally was due to poor detection of potential organ donors by ICU staff. Kim *et al*, (2006) conducted a large survey of Korean intensive care nurses (N=520). The aim of the study was to develop a reliable and valid scale to quantify Korean ICU nurses' attitudes regarding brain death and organ transplantation.

Kim *et al's* (2006) study was designed using two distinct phases; phase one was the development and validation of items for the attitude scales and phase two consisted of a distribution of a questionnaire to the ICU nurses. The survey attracted a high response rate of 92%, with 70% of respondents having experience of caring for at least ten brain dead patients. Interestingly, 89% of the respondents [Korean ICU nurses] reported never attending any training seminar / session relating to brain death and organ transplantation. Following inspection of the grouped items, Kim *et al* (2006) findings suggest that there were four components; discomfort, enhancing quality of life, willingness to be a donor and rewarding experience. Consequently, these four themes provide strong evidence that some critical care professionals have 'discomfort' with organ donation and is worthy of further research.

In summary, the studies by Collins (2005), Cantwell and Clifford (2000) particularly, highlight that anxiety arises from mixed feelings and doubt towards organ donation following end of life decisions. Moreover, Kim *et al* (2006) conclude that further research is needed to explore whether a positive correlation exists between nurses' attitudes towards brain death

and organ donation and their actual behaviour. The proposed research intends to examine critical care staff attitudes towards brain stem death and brain stem death testing through a series of associated semi-structured interview questions. Equally, the narrative review provided little evidence that specifically focuses on critical care staff interactions with relatives / carers during the actual organ donation process.

2.5.4 Theme 4: Relative / Carer Experiences

Another theme identified from the narrative review included the relative / carer experiences of the organ donation request. A number of papers that explored the experiences of relatives regarding the donation process were located. For example, qualitative research by Manzari *et al*, (2012) investigated families' experiences of an organ donation request following brain death. Data were collected through 38 unstructured and in-depth interviews with 14 consenting families and 12 who declined to donate organs. A purposeful sampling process began in October 2009 and ended in October 2010. Data analysis led to two major themes listed as: 1) serenity in eternal freedom; and 2) resentful grief. The central themes were peace and honour versus doubt and regret. However, this was an Iranian study, the research emerging from a country with strong Muslim values. Indeed, Iran does not allow organ donation from patients that have planned withdrawal of life sustaining treatment (Donation after Circulatory Death).

Additionally, Orøy *et al*, (2015) explored healthcare professionals' experience of ethics related to care and interaction with critically ill patients with severe brain injuries and their families. A hermeneutic phenomenological approach was adopted in two ICUs in a Norwegian University affiliated hospital, identified for data collection. A total of 12 cases were observed with 32 healthcare professionals involved in the study. Findings suggested that

levels of anxiety increased amongst relatives when information about the organ donation process was withheld.

In conclusion, the study by Orøy *et al*, (2015) affirms the difficult ethical issues that healthcare professionals grapple with relating to care of dying patients and the medical intention to “save life”. Furthermore, organ donation was referred to as the “*dark side*” suggesting that organ donation was in conflict with fundamental caring values of the nurse. The study claims that less experienced nurses may need enhanced mentoring not only for the practical tasks but in developing moral reasoning and reflection skills. These findings suggest that less experienced nurses find the donation discussion uncomfortable. There is a significant link between the study by Orøy *et al* (2015) and the earlier studies by Meyer *et al*, (2012) and Jacoby *et al*, (2005), which reinforces the importance of how staff training creates an empowered donation workforce.

In contrast, a study by Brown *et al*, (2010) explored the barriers that exist when obtaining consent from potential organ donor families utilising a retrospective cohort study. Brown *et al*, (2010) assert that family consent represents an important limiting factor for successful donation. Brown *et al*, (2010) hypothesised that specific barriers to obtaining family consent can be identified and improved upon to increase organ donation consent rates. The purpose of their study was to compare families who declined organ donation to those who granted consent, specifically to identify barriers to family consent for successful organ donation.

Brown *et al's*, (2010) methodology included a 4-year (2004-2007) retrospective study of potential organ donors covered by the regional organ procurement organization (OPO). Variables collected included age, gender, race, cause of brain death (trauma V's medical) of the potential organ donor and elapsed time from declaration of brain death to family approach by OPO. Potential organ donors whose family declined organ donation (DECLINE group)

were compared with potential organ donors whose family consented to organ donation (CONSENT group).

Brown's *et al* findings indicate that family members of minority populations, medical brain deaths and older potential donors more often decline consent for organ donation. Family education and resource utilisation toward these specific populations of potential organ donors may help to improve organ donation consent rates. In addition, delayed family approach by OPO seems to be associated with decreased consent rates. System improvements to expedite family approach by OPO may likewise lead to improved consent rates. Brown *et al*, (2010) assert the correlation between families declining donation and failure to utilise expertise (SNOD) in the donation discussion. Moreover, the study reinforces the need for future research to explore the factors that influence critical care staff to consider approaching relatives for organ donation following the death of a patient.

Furthermore, Polikoff and McCabe (2013) investigated end of life decisions in the paediatric ICU, focusing on the requirements of families following EOL decisions. Polikoff and McCabe assert that communication between "care providers, patients, and families is essential" to excellence in EOL care. This discussion paper is not original research, rather a summary of previously conducted research. However, one salient argument from this paper is that bereavement is not experienced exclusively by families of children who die but also by critical care professionals. Further research is needed to determine whether the emotional turmoil experienced by some critical care professionals influences the decision to donate by relatives.

Similarly, for members of the critical care team, the death of a child is emotionally, psychologically and physically challenging, as identified by Polikoff and McCabe (2013). Even before considering the option of organ donation, Polikoff and McCabe suggest that the

critical care team endure a turbulent episode, suggesting the introduction of organ donation has the potential to further exacerbate this emotional drain. Interestingly, organ donation as a concept is not mentioned within this discussion paper and perhaps this is related to the aforementioned staff discomfort with organ donation following end of life decisions. The paper by Polikoff and McCabe (2013) discusses the needs of the family prior to and during EOL decisions but fails to establish the needs of families post EOL care, including the potential for organ donation. This concept was also investigated by Stroud (2002) who argued that whilst there is now recognition that relatives of patients who die in intensive care need ongoing support and care, there is little to suggest that the emotional needs of the critical care team are catered for.

Additionally, Lloyd-Williams *et al*, (2009) undertook a qualitative study with relatives of patients who had died from brainstem death in an ICU. A total of 20 ICU were recruited for the study and a purposive sampling technique was used to collect data. A total of 130 patients' relatives were approached, and 30 (22%) agreed to be interviewed. Overall, the participants reported on the value placed on the physical care of their relative but poor communication and breaking bad news was a cause for concern.

Furthermore, St Ledger *et al*, (2013) explored moral distress in relatives, doctors and nurses during end of life care decision making. Adopting a narrative inquiry case study approach, the study conducted a series of in depth interviews. Rather than focusing on presumed moral distress, investigating what influences critical care staff to consider engaging with relatives about organ donation following end of life decisions would add an original dimension to my study. The article by St Ledger *et al*, (2013) provides clear evidence that moral distress is experienced by critical care staff when caring for potential donors. The evidence base indicates that moral distress amongst ICU staff, if unresolved, is a potential barrier to organ donation and my study will investigate this in more detail.

2.5.5 Theme 5: The Organ Donation Request

Having established the significance of the support needed for the relatives of dying patients, this section presents the evidence around approaching of relatives / carers with an organ donation request. Orøy *et al*, (2013) found in their small scale study of 9 cases in 2 Norwegian ICU's, that judging when was the best time to approach a distressed family with an organ donation request, stimulated great anxiety amongst critical care staff. Orøy *et al*, (2013) discovered that doctors and nurses use subjective measures to determine whether a family was ready for the donation discussion, such as assuming that simply notifying the family of the planned brainstem death testing adequately prepares them for the tests.

Conversely, Sque *et al*, (2008) conducted qualitative research to better understand the reasons why relatives decline organ donation. Sque *et al*, (2008) adopted a retrospective, cross-sectional, qualitative series of interviews with 26 relatives who had declined the option of organ donation. The study concluded that donation decisions were dependant on a number of converging elements with the desire to "protect the dead body" as the chief reason why relatives declined organ donation. Interestingly, Sque *et al*, (2008) does suggest that the way in which families / relatives are treated at the time of the donation has been shown to affect donation decisions, but this was not explored in any detail. However, scrutiny of further research papers (Matten *et al*, 1991; DeJong *et al*, 1998; Sque *et al*, 2003) highlights a tangible 'gap' in fully understanding how initial dialogue by critical care staff, with potential donor families, affects donation decisions.

In a similar way, Berntzen and Bjørk (2014) investigated the experiences of donor families after consenting to organ donation. Unlike the findings from the research conducted by Sque *et al*, (2008), Berntzen and Bjørk (2014) suggested that healthcare professionals are key people in contributing to understanding with a donor family. Although families' experience

of the organ donation process was not the objective of the study, most relatives spoke of this. This study suggests that the relative's readiness to engage and transition towards end of life care is reported as a significant influence on the organ donation approach.

2.5.6 Theme 6: Transition to End of Life Care

Studies by Coombes *et al*, (2012) and Cook *et al*, (2003) highlight that the transition to end of life care is significant because this is the starting point for approaching relatives with an organ donation request. For example, qualitative research by Coombes *et al*, (2012) explores the challenges health care professionals face in transition from intervention to end of life care, adopting a qualitative method of enquiry to explore human experience and emotion. The study by Coombes *et al*, (2012) uses single semi-structured interviews, with 13 medical and 13 nursing (N = 26) staff drawn from two Intensive Care Units (ICU) in a large university affiliated hospital in England.

Coombes *et al*, (2012) report that 67 potential end of life cases were identified during the recruitment phase but only 35 met the inclusion criteria. The rationale for exclusion, following a retrospective examination of the medical notes, included extreme grief (N = 12), complex family issues (n = 10) and police / coroner involvement (N =10). The staff involved in the care of the eligible 35 cases were sent recruitment packs inviting them to participate in the study. The researchers, however, do not provide adequate justification for excluding the 32 other cases.

Similar to the study by Coombes *et al*, (2012), Cook *et al*, (2003) conducted a large quantitative study of adults who were receiving mechanical ventilation in 15 intensive care units, recording baseline observations, type of life support, the use of do-not-resuscitate

orders and physicians' prediction of the patient's status. The aim of the study was to determine the relationship between these factors and withdrawal of mechanical ventilation, using Cox proportional-hazards regression analysis. Of the 851 patients who were receiving mechanical ventilation, 539 (63.3%) were successfully weaned, meaning the patient began to breath spontaneously without support from the ventilator (the patient survived). However, 146 (17.2 %) patients died whilst receiving mechanical ventilation and a further 166 (19.5%) had mechanical ventilation withdrawn.

Cook *et al*, (2003) prospectively followed consecutive patients above 18 years of age who were expected to be in ICU for greater than 72 hours. Withdrawal of mechanical ventilation was defined as the discontinuation of mechanical ventilation in anticipation of death. The results from the study suggest that rather than age, severity of the illness or organ failure, the strongest determinants of the withdrawal of ventilation in critically ill patients were the physician's perception that the patient preferred not to use life support and the physician's predictions of a poor neurological outcome. This research affirms that clinician's perceptions are actively involved in the decision to withdraw life-sustaining treatment (WLST).

Cooke *et al*, (2003) and Coombes *et al*, (2012) collective findings echo previous papers reported in theme 5 that the approach for organ donation generates anxiety. The research by Cook *et al*, (2003) and Coombes *et al*, (2012) provides evidence that patient presentation and medical condition holds a significant influence on ICU clinician's actions and experiences. Further investigation is needed to determine whether clinical judgements and perceptions of critical care nurse and doctors influence organ donation decisions by relatives.

2.6 Narrative Review Conclusion

The narrative review highlighted a relatively small number of studies but clearly demonstrates that the experiences of critical care staff regarding organ donation following the death of a patient is a poorly understood phenomenon. There was a relationship between education / training and positive ICU staff perceptions of organ donation (Lin *et al*, 2014; Meyer *et al* 2012; Munthy *et al*, 2012; Camut *et al*, 2010; DoH, 2008; Jacoby *et al*, 2005). When comparing the use of protocols and policies to enhance donation, organ donation referral rates increased and the presence of the SNOD appeared to positively influence donation outcomes (Citerio *et al*, 2016; Garside, 2011).

The narrative review also suggests that ICU staff attitude does affect donation outcomes and interactions with potential donor families (Flodén *et al*, 2011; Zampieron, 2010; Kim *et al*, 2006; Collins 2005; Cantwell and Clifford, 2000). However, there are noted limitations here as the attitudinal studies were mostly conducted prior to the Organ for Transplant Report (DH 2008) which radically overhauled staff training and education within acute UK hospitals.

The studies also provided evidence that relatives / carers are making donation decisions under incredibly difficult circumstances. Additionally, ambiguity with the information provided by ICU staff directly impacts on final decisions (Orøy *et al*, 2015; Polikoff and McCabe, 2013; Manzari *et al*, 2012; Brown *et al*, 2010; Lloyd-Williams *et al*, 2009). The literature found a direct relationship between ICU staff anxiety and fear with the organ donation request but not investigated in any great detail (Orøy *et al*, 2015; Berntzen and Bjørk, 2014; Orøy *et al*, 2013; Flodén *et al*, 2011).

In conclusion, the key findings from the narrative review indicate that the experiences of critical care staff approaching relatives for organ donation following the death of a patient is a poorly researched phenomenon. Equally, the narrative review identified a gap in the knowledge base concerning critical care staff experiences of organ donation at the actual time of the donation request. The narrative review provided focus on various methodological approaches used to conduct research and the next chapter presents the research methodology used in my grounded theory study.

Chapter 3: Research Methodology

3.1 Introduction

This chapter presents the research methodology that underpins the research design of the study. The research methodology is introduced, including a brief discussion of the research paradigm, study design, sample, data collection methods and ethical considerations. This chapter places the research methodology in context, with an analysis of the research theory, philosophies and formal processes which have guided the development of my study. The methodology was influenced by a constructivist grounded theory (CGT) approach. I will identify the origins of grounded theory (GT) and explore the original approach to GT as offered by Glaser and Strauss (1967). Methodology is defined as a set of guiding principles that influence the design of the study (Birks and Mills, 2015).

Furthermore, my role as a researcher is influenced by the methodological framework and underpinning philosophy. As a constructivist, it is important to recognise how I interact with the participants, in other words the position I take in the study. As the researcher, it is important to make explicit these philosophical beliefs because it will provide a coherent rationale as to how my selected methodology fits with my research study (Bryant and Charmaz, 2007).

Theoretical and philosophical frameworks known as paradigms replicate interconnected beliefs about the world and how they are interpreted and analysed (Reay *et al*, 2016). They are composed of ontology (what is the nature of reality), epistemology (what is the nature of knowledge) and methodology (study design) (Birks and Mills, 2015; Sapsford and Jupp, 2006; Denzin and Lincoln, 2003; Crotty, 1998). These beliefs about reality and the nature of

knowing can help unite a coherent philosophical framework, providing a robust platform to shape the research process and study design (Crotty, 1998).

I outline my world view which influences my position in the research and ultimately the design of the study. My philosophical beliefs about the social world are rooted in the constructionist / interpretivist paradigm which recognises that reality is constructed by those who experience it. Thus constructivist grounded theory is considered to be a process of reconstructing that reality (Charmaz, 2006; Birks and Mills, 2015). Conversely, ontological realism signifies a belief that reality exists independently of human experience and action. It is aligned with the positivistic paradigm developed from traditional scientific technique (Lincoln and Guba, 2000). This latter approach seems incongruent with the overall aims of the research because the study explores human experience and emotion, which is not easily captured by the positivistic research paradigm.

In contrast to a positivistic approach to reality, interpretivist theory allows the researcher to “*interpret our participants’ meanings and actions and they interpret ours*” (Charmaz 2006; p 127). This approach is congruent with the research aims of the study which is to explore critical care staff experiences regarding approaching relatives for organ donation following the death of a patient. To ensure a robust research design, it is important to select a research paradigm that is consistent with my belief in the nature of social reality (Mills *et al*, 2006). Epistemologically, constructivist grounded theory (CGT) accentuates the subjective relationship between me as the researcher and the participant, together co-constructing social reality (Charmaz, 2006; 2014). My study explores the experiences of critical care staff regarding the organ donation request following the death of a patient in their care. Therefore, in order to do this effectively, I need to understand the social world and co-construct a social reality as experienced by the participants and researcher. In summary, understanding

ontological and epistemological assumptions influence the methodological approach to research and ultimately the research design of the study.

3.2 Methodology

Constructivist grounded theory relies on a qualitative approach to the research process. Conversely, quantitative research focuses on supporting research that aims to provide numerical data and statistical representation (Moule and Goodman, 2014). Qualitative methodology is appropriate because it explores individual human experience and perception (Richards, 2015; Bernard and Ryan, 2010) and will enable the investigation of not only what critical care staff *do* but also the rationale underpinning these actions. Strauss and Corbin (1998) reinforce the benefits of using GT as it illuminates the detail of human experience and supports the development of new theory. This approach is congruent with the research aims outlined in Chapter 1 (page 18) because the study seeks to explore critical care staff experiences. In addition, the narrative review of the literature (Chapter 2) identified a gap relating to the experiences of critical care staff regarding the organ donation request following the death of a patient. This suggests that there is little understood about how critical care staff influence donation decisions.

Grounded theory is located in the positivistic tradition and views data as objective facts concerning a knowable world (Charmaz, 2006). Traditional grounded theory asserts that data already exists in a known world and a researcher finds them and *discovers* theory from them (Glaser and Strauss, 1967). In contrast to constructivist grounded theory, classical GT remains divorced and distant from research participants and their social realities. However, a constructivist approach does not conform to positivistic philosophy, instead recognizing “*diverse local worlds and multiple realities*” (Charmaz, 2006; p 132). Thus, in selecting this

methodological approach, constructivism aims to illuminate the complex nature of social worlds, experiences and actions. The ability to achieve objective detachment as specified by the positivistic approach is questionable. Decision making, in any context, is influenced by and representative of many past and present insights, knowledge and experiences (Birks and Mills, 2015). This is intensified when the researcher originates from the profession which is the focus of inquiry and has developed a body of professional knowledge (Bryant and Charmaz, 2007; Charmaz, 2006). This makes it impossible for me not to give forethought to the study and participants before starting, therefore I am unable to enter the research as a “*blank slate*” (Charmaz, 2006; p 3).

Other research methodologies within the qualitative paradigm were considered, however they were not practical. I explored ethnography which offered the possibility to observe the interaction between critical care staff and potential donor families. However, ethnography would have been challenging because organ donation is a relatively rare phenomenon, as outlined in Chapter 1, and practically it would not be possible to know when the potential for organ donation would arise. Secondly, and more importantly, my presence could influence the support and decision making process of relatives. Phenomenology was considered and eventually rejected because I was not confident this methodological approach would provide a suitable framework of support during the research process.

3.3 Grounded Theory

Following deliberation of other potential methodologies, I decided that Grounded Theory would be a suitable methodology as it is a systematic, inductive and comparative approach for conducting inquiry for the purpose of constructing theory (Bryant and Charmaz, 2008; Charmaz, 2014). It is clear from the narrative review in chapter 2 that critical care staff

experiences of organ donation following the death of a patient is a poorly understood phenomenon. An example, in their seminal work *Awareness of Dying*, Glaser and Strauss (1965) explored the interaction between hospital staff and dying patients. Following this study, Glaser and Strauss (1965) produced a paper entitled 'The Constant Comparative Method of Qualitative Analysis', providing the foundation for *The Discovery of Grounded Theory* which was published in 1967 (Glaser and Strauss 1967; Bryant and Charmaz 2008).

Glaser and Strauss conducted the study of dying during the 1960's, an era when quantitative methodologies, driven by 'positivist' assumptions, led approaches to scientific enquiry (Glaser and Strauss, 1967). It is suggested, by its very nature, that research at this time was largely deductive and centered upon testing rather than developing theory (McCrae and Purssell, 2016; Eaves, 2001). For example, by measuring variables, researchers would test hypotheses allowing them to generate the esteemed powers of prediction and control (Glaser, 1978). Subsequently, this particular period was characterized by 'impressionistic, anecdotal, unsystematic, and biased' qualitative research (Charmaz, 2006).

Grounded Theory Methodologies have developed along divergent paths, each distinct, but many have commonality. Glaser (1978) maintains that his earlier theory, defining GT as a method of discovery and treated categories as emergent from the data. However, Strauss (1987) developed his belief towards 'verification' and working with Juliet Corbin provided the catalyst needed for the GT development, because their theory assumes the researcher to be an instrument of data analysis (Cutcliffe, 2000). Strauss and Corbin's (1990) description of GT introduced the concept of new technical processes rather than focusing on the earlier 'constant comparative' strategy. Conversely, Glaser (1992) claims that Strauss and Corbin's model of GT forces data into preconceived categories, contradicting the essence of grounded theory discipline.

Since this time, a number of scholars have contended the positivistic approach outlined by both Glaser and Strauss and Strauss and Corbin (Charmaz 2000, 2002, 2006; Clarke, 2003). Adele Clarke (2005) adopted an explicit post-modern approach to GT using situational analysis to investigate the discourse within the inquiry. Although her book was a fascinating read, I decided not to use a Clarke (2005) situational approach because I felt that her radically different conceptual infrastructure and focus upon situations, context and discourse only partially fulfilled the intentions of my study. Furthermore, CGT provided me with structure and support during the methodological process which I needed at this stage in my development as a researcher.

3.4 Constructivist Grounded Theory

Charmaz built on the classical work by Glaser and Strauss (1967) and was influenced by the seminal writing *Social Construction of Reality* (Berger and Luckmann, 1967) and the desire to emphasize reflexivity and sharing of social reality (McCrae and Purssell, 2016). However, the defining principles of GT remain relatively constant in both traditional GT (Glaserian and Straussian) and the constructivist approach developed by Charmaz (2006). Using the framework as advised by Charmaz (2006), my research uses semi-structured interviews to elicit data from participants. Next, Charmaz (2006) encourages data sorting and summarizing initial codes. Further coding and analysis allows the emergence of categories. The next step is to inspect the categories for links and relationships using theoretical coding, transforming data from analytical to theoretical. The approach by Charmaz (2006) allows exploration of *social reality* as experienced by critical care staff. An additional benefit to Charmaz (2006) method of GT is the writing of field memos which encouraged the development of thought and observation during the data collection process. From the outset of my research journey,

the study has adopted a constant comparative method which includes comparing notes, codes, categories and memos leading to new theory generation (Glaser and Strauss, 1967; Charmaz, 2006; 2014).

3.5 Research design

3.5.1 Ethical Considerations

As discussed in Chapter 1, organ donation is an emotive subject and ethical considerations played a fundamental part throughout the life of my research project from initial planning of my study, the data collection process and the way in which data was handled and protected (DH, 2011). Additionally, qualitative researchers have the potential to impact more on people's lives than researchers who collect data impersonally and record it numerically (Richards, 2015). My study involves human subjects (critical care staff) and an insight into their personal social world, it was therefore essential to obtain ethical approval prior to data collection commencing, thus ensuring safety and welfare of all participants (The Code, 2015; Sapsford and Jupp, 2012; DoH, 2011).

It is acknowledged that qualitative research encourages people to talk about sensitive issues and concerns which have the potential to cause emotional distress and anxiety (Dempsey *et al*, 2016; Birks and Mills, 2015). Asking the participant to recall potentially distressing and painful experiences concerning their clinical practice could cause long term and unintended harm (Richards, 2015; Sapsford and Jupp, 2012). Consequently, each participant was informed of this risk prior to the interview commencing and their participant information sheet had appropriate support numbers / email contacts (occupational health department and staff support telephone number) should they experience any unresolved issues. Equally, any sensitive issue raised would be discussed during doctoral supervision meetings, ensuring an

appropriate and professional response to specific concerns (Dempsey *et al*, 2016; Birks and Mills, 2015).

Ethical approval was gained from the University and further ethical approval was obtained from the Hospital Trust. Also, ethical approval was obtained from NHS Blood and Transplant (Appendix 6, 7 and 8). In addition, professional standards were considered and the Nursing and Midwifery Council Code (The Code NMC, 2015) was observed at all times, ensuring the safety and protection of the public. I also completed a Disclosure and Barring Scheme (DBS) Enhanced Check (formerly Criminal Records Bureau), mindful that the sensitive research (see below) and proposed one-to-one interviews carried risk without appropriate checks being evident. The Department of Health (2011) asserts that all participants in research have the right to expect the protection from physical, psychological and economic harm at all times during the study.

The ethical approval granted by the University included a statutory participant consent form (Appendix 11) which I completed at the start of each interview, requesting each participant to sign. Prior to the interview commencing, it was affirmed that the participant had the right to withdraw consent from study, at any point, without providing a reason or fear of reprisal.

In addition, each potential participant for the study was provided with a participant information sheet (Appendix 9) which clearly identified the aims and objectives of the research. Furthermore, the information provided allowed each participant to make an informed decision on whether they wished to take part. There was no pressure from me as the researcher, each participant was allowed time to make decisions and an email address and telephone number was provided for further questions.

There were no issues concerning capacity to give consent as all participants would be registered practitioners with the appropriate regulatory body (Nursing and Midwifery Council / General Medical Council).

3.5.2 Sensitive Research and the Grounded Theory Study

Health research studies that fall into the categories of rape, drug use, violence, death, grief and birth can be regarded as sensitive topic areas (Dempsey *et al*, 2016). Sensitive research is a complex phenomenon and challenging to define but is often a taboo topic or one of those “*laden with emotion or which inspire feelings of awe or dread*” (Lee, 1993: p 6). Therefore, my GT study needed an appropriate assessment of risk faced by participants. Although critical care staff sharing their personal experiences and feelings relating to death and organ donation does carry an element of risk, avoiding this research could be regarded as an “*evasion of responsibility and disempowering to the individuals involved*” (Dempsey *et al*, 2016; p 482).

Dempsey *et al* (2016) developed a Framework of Essential Elements in Qualitative Interviewing. Their research, which preceded development of the framework, centered on increasing understanding of family carers’ experience of providing end of life care for those dying with dementia at home. The framework ensures that researchers consider the potential risk to participants when planning and conducting interviews on sensitive topics (Liamputtong, 2007).

The first component needing consideration was the preparation, planning and implementation of an interview schedule. Dempsey *et al* (2016) recommend that an interview schedule with predetermined questions is used in conjunction with the most appropriate research

methodology. They advise that the interview schedule be used flexibly to facilitate meaningful discussion between the researcher and participant. Secondly, I considered the use of a “gatekeeper” to access the sample (critical care staff). As discussed in more detail below, the “gatekeeper”, which I refer to as third party support, was the embedded Specialist Nurse Organ Donation (SNOD) who alerted me if any participant was identified for the study. The third party support was fully briefed regarding the aims and objectives of the study.

Thirdly, I considered the impact of the data collection method on the participant and ensured the time and location of the proposed interview was agreeable with the participant. Dempsey *et al*, (2016) stipulate that the fourth and fifth element of the framework centres on the need to establish a rapport with the participants through therapeutic interviewing. These particular elements support my methodological approach (CGT), as the building of a therapeutic relationship with participants will enhance the co-construction of social reality (Charmaz, 2006; 2014).

My fourth consideration, as advised by Dempsey *et al*, (2016), was that distressed participants should be anticipated and refreshments, tissues and a private room free from disruption should be available. Each participant was issued with a Participant Information Sheet which had my contact details and a number of contacts for welfare and support (occupational health and staff support helpline). These professional points of contact would be useful if the participant displayed signs of distress during the interview. Finally, Dempsey *et al*, (2016) encouraged me to conduct the research within the confines of the ethical approval conditions (outlined above).

3.5.3 Data Management and Confidentiality

The final element of the ethical considerations was data management following the participants' imparting of information. Each participant was informed how the information provided would be handled and stored. Data was captured using a digital recording device with reassurance that the saved file would be deleted following interview transcription. Each taped interview transcript and the signed consent form was kept in a locked cupboard within a locked office at the University where I currently work. Each participant was informed that their name would be replaced with a pseudonym for the purpose of interview transcription. If the respondent discussed a patient's name, clinical case or other identifiable data such as name of the ward, the participant was reassured this would be omitted from the interview transcription (Data Protection Act, 1998; Oliver, 2014). The protection and welfare of participants was of fundamental importance prior to them providing data for the study.

3.6 Data Collection Method

Consistent with a constructivist grounded theory approach to the research, it was important to identify how I, as the researcher, constructed meaning from experiences and perceptions shared by participants (Charmaz, 2006). As outlined in Chapter 1, the study had a series of research questions I intended to explore. In order to understand what influenced the critical care staff approach to the organ donation request following the death of a patient, the data collection methods must be transparent. It was my intention to encourage participants to express their own meaning and interpretation of events, therefore I elected to use an interview approach (Grbich, 1999; Bernard and Ryan, 2010; Richards, 2015).

Charmaz (2006) asserts that interviews help direct conversation and provide opportunities for an in-depth exploration of a particular topic with participants (Charmaz, 2006). The interview schedule was, in part, informed by the narrative review in Chapter 2 which provided key concepts and ideas I wished to explore in greater detail. Traditional grounded theorists argue that this approach has the potential to bias the data (Glaser and Strauss, 1967), however, Charmaz (2006) argues it is useful to stimulate generation of research questions which, in turn, supports participant disclosure of critical information.

Interviews, therefore, become a mechanism for the production of shared knowledge between the researcher and participant (Charmaz, 2006). Regardless of the position taken by the grounded theorist, during the narrative interaction, researcher and participant “*give and take from each other*” (Birks and Mills, 2015; p 56). Epistemologically, as a constructivist, I believe it is difficult to separate the researcher from the participant during the data collection. Equally, Charmaz (2006) argues that the co-construction of social reality is a shared process with the researcher and participant. The role of the researcher as the data collection instrument is significant as they develop theoretical sensitivity through co-construction of social reality hence this is explored in the next section.

3.7 Developing Theoretical Sensitivity

Theoretical sensitivity can be described as the ability of the researcher to recognize and extract, from the data, the elements that have relevance for the emerging theory (Birks and Mills, 2015; Mills *et al*, 2006). In their book *The Discovery of Grounded Theory*, Glaser and Strauss (1967) argue that the sociologist [researcher] should be sufficiently theoretically sensitive which, in turn, supports the conceptualization and formulation of theory as it emerges from the data. Charmaz (2006) adapts this stance by suggesting that the act of

becoming theoretically sensitive involves ‘*Theorizing*’ (p 135), describing this as being able to recognize and establish connections in the data. In their book *Basics of Qualitative Research*, Corbin and Strauss (2008) devote an entire chapter on the subject of theoretical sensitivity. They report on the importance of theory development through the researcher’s detection of what is meaningful and significant in the data.

Becoming theoretically sensitive to the data is significant because my professional experience in the field of organ donation means that I have acquired a substantial body of theoretical knowledge about the organ donation process. According to traditional grounded theorists there is potential for the researcher to consciously or unconsciously apply existing theoretical knowledge to the data collection process (Glaser, 1992). One method to enhance theoretical sensitivity is to ensure a robust inspection of the literature during the analytical process.

Through the comparison of theoretical concepts in coded data, Strauss and Corbin (1990) argue that the literature can justifiably become a source of data itself. Likewise, (Charmaz, 2006) asserts that developing theoretical sensitivity encourages the identification of connections in the data. Sensitizing concepts from the narrative review (Chapter 2) were incredibly useful in the study, contributing to the research proposal for ethical approval and I recognise that this evidence of knowledge could and should influence the analytical process. In doing so, I also reflexively noted my influence in the development of the interview schedule and believed that this should be carefully explicated.

3.8 Developing the Interview Schedule

The intention of the study was to encourage critical care staff to provide narrative during interview and the interview guide was helpful to identify initial areas for exploration.

Developing the interview guide helped me deliberate over concepts which needed to be

included for further exploration and how the questions should be phrased. It is advised that early interview questions should be easy to answer and constructed to help relax the participant, for example, factual data such as name and professional experience (Moule and Goodman, 2014; Richards, 2015). This encouraged me to develop my first interview question:

Question 1: Tell me about your background and experience as a nurse / doctor.

The interview guide was designed to be flexible which allowed the probing of responses to certain questions. Probing during the interview is a well established technique that can elicit more information or provide clarity on responses provided (Bernard and Ryan, 2010). It was at this junction that I reflected that grounded theory provided an appropriate methodology because of its flexibility during the data collection process.

The narrative review was helpful in the identification of some key questions to consider within the interview schedule, however I started to use my previous experience as a Specialist Nurse – Organ Donation (SNOD) to influence the development of the schedule. I was reassured that Charmaz (2014) advocates constructivist grounded theorists to incorporate reflexivity within the research design, because it is an active process that a researcher can use to gain insight into the subject and enhance theoretical sensitivity (Birks and Mills, 2015). Hence, incorporating a reflexive agenda that seeks to find multiple vantage points on my research, in particular constructing the interview questions, falls within the remit of those who have positioned themselves methodologically as constructivists (Birks and Mills, 2015; Charmaz, 2006; 2014).

Furthermore, I wanted to incorporate a reflexive agenda and obtain multiple perspectives on which questions should be included in the interview schedule. The decision was taken to meet with a family who had experienced being asked to consider organ donation following

the death of their son. The rationale for this decision was to ensure that the service user (donor family) remained at the heart of the study (McLoughlin, 2009). A letter was drafted and sent to the donor family home asking if they would consider supporting the study. They responded and a meeting was arranged at the family home. In the interest of data protection and confidentiality, the donor family name has been changed (Data Protection Act, 1998; The Code NMC, 2015). Mr and Mrs Smith had previously consented to organ donation from their son following his tragic and sudden death aged 24. Since this time, Mr and Mrs Smith have devoted time developing a charity and educational initiatives to promote organ donation, at a local and national level. Before conversation started, the study aims and objectives were discussed and consent was gained for their experiences to be shared. The input of the donor family was significant as their unique experience of the organ donation request helped me develop theoretical sensitivity. Essentially, the input of a donor family allowed me to work reflexively and consider how my previous professional experiences could influence the interview schedule.

During the meeting, Mr and Mrs Smith shared their personal experiences of losing a child and the way his death and organ donation was sensitively handled. Their experience was useful in the construction of interview questions as they had direct experience of their son having brain stem death tests performed and being asked to consider organ donation by critical care staff. It was the direct input of Mr and Mrs Smith that influenced the interview schedule questions. For example, Mr and Mrs Smith thought it important that critical care staff were asked if they would allow relatives / carers to observe formal brain stem death testing (see question 6 below). Similarly, the narrative review had also identified death / dying and anxiety as core categories so this seemed a significant issue to explore, hence a question about brain stem death testing and how this influenced decision making was included (question 6). A full list of the interview questions is located in the Figure 3.1 below:

Figure 3.1: Interview schedule

Question 1:

Tell me about your background and experience as a nurse / doctor

How many times have you cared for a potential organ donor?

Question 2:

Can you describe what happened when the decision was made to withdraw life sustaining treatment on a patient in critical care?

Question 3:

Do you think the patient's age, medical condition and cause of death had any bearing on the decision to withdraw life sustaining treatment?

Question 4:

Is there any time when you believe (d) that organ donation should not be considered?

Question 5:

Can you tell about the skills you have used when identifying a potential organ donor?

Question 6:

Please describe how you feel about relatives / carers witnessing formal brain stem death testing?

Question 7:

Would you allow your organs to be donated for use in transplant operations?

Question 8:

Would you accept a lifesaving organ transplant for yourself or a member of your family?

Question 9:

Can you reflect upon a time when a patient was referred to the on call Specialist Nurse – Organ Donation as a potential donor?

Question 10:

Can you recall a time when a family was very upset with the situation and do you think their grief influenced the decision to donate or not?

Question 11:

How does the language we use when a patient is at the end of life influence decisions made by relatives / carers? Would you change the way in which you approached the relative?

Question 12:

Do you ever have any concerns or anxiety about the referral for organ donation or organ donation in general?

Strauss and Corbin (2008) state that interview questions within grounded theory studies should be open and evolve during the interview process. This position fits with the use of ancillary probing questions to elicit more data from the participant. In the same way, Charmaz (2006) affirms that the function of the researcher during an interview is to explore concepts rather than interrogate. Similar to the concept of reflexivity described above, Corbin and Strauss (2008) advise the use of self-reflection to ensure that meaningful interview questions are developed. The next stage of the data collection method was to consider who needed to be included in the sample in order to generate meaning and understanding about critical care staff experiences of approaching relatives for organ donation following the death of a patient.

3.9 Sample

The constructivist positioning aspires to achieve the objective of answering the research question through understanding the uniqueness of the social world (Charmaz, 2006). As identified by Richards (2015) and Morse (2000), qualitative research has no proven technique in determining the specific number of participants for a study. Hence, unlike traditional positivistic approaches to research, the size of the sample is subjective (Marshall *et al*, 2013) and should be based on the need to sufficiently address the original research question with an aspiration of achieving data saturation. According to Charmaz (2006), data saturation is reached once there are no new concepts or themes emerging from the data (Bryant and Charmaz, 2007). However, data saturation is a contentious issue within grounded theory studies and this is discussed further in section 4.9 below.

Moreover, a defining characteristic of grounded theory studies is that sampling is often determined by the data analysis process and theoretical saturation, influenced by the emerging codes (Strauss and Corbin, 2008). In other words, saturation is achieved once the researcher is at the point of diminishing returns, when nothing new emerges from the data. Whilst there is no fixed agreement on the sample size for grounded theory studies, other factors can be considered to reach saturation including the quality of interviews and researcher experience (Marshall *et al*, 2013).

I selected purposive sampling for this study because the study aimed to ‘sample’ critical care staff because they had experience of organ donation following the death of a patient in their care (Charmaz, 2007; Moule and Goodman, 2014). Furthermore, purposive sampling ensured the focus was on suitability rather than size of the sample and critical care staff were needed to ensure the findings were meaningful and relevant. Often, this method of sampling is referred to as judgment sampling, as the researcher is making judgments about the configuration of the sample (Bryant and Charmaz, 2007).

I had anticipated that approximately 10 critical care staff members would be recruited for the study. This decision was influenced by previous research, for example, Sque *et al*, (2008) who explored the reasons why relatives declined the option of organ donation, used a similar number of participants for their study. Data collection commenced during 2015 and continued over a 14 month period. Typically, each interview was conducted over a 60 minute period. As the interviews progressed, theoretical sensitivity was employed to detect links and interesting leads in the data.

In a similar way, a professional doctorate study by Templeman (2015) explored critical care nurses’ experiences following the decision to withdraw life-sustaining treatment using a purposive sample of eight nurses from a large 20 bed ICU in the North of England. As the

research process progressed, theoretical sampling was used to allow the emerging data to influence the path of inquiry (Bryant and Charmaz, 2008; Charmaz, 2006; 2014; Reay *et al*, 2016). This is significant because, as Bagnasco *et al* (2014) contend, ‘size’ does not mean ‘significance’ (p 6). Equally, Bagnasco *et al* (2014) suggest that:

“With grounded theory strategies, theoretical development turns on theoretical sampling. The researcher collects new data to check, fill out, and extend theoretical categories. Hence, theoretical sampling fits into the research and analytical process much later than initial sampling of sites, people or documents”

(p 6).

Thus, Charmaz (2006) suggests that theoretical sampling shapes further data collection as the researcher pursues developing conceptual ideas rather than amassing general information.

3.10 Sample Site

The sample was selected from a large regional teaching and university affiliated hospital, located in the North of England. As discussed in Chapter 1, organ donation occurs within specific areas in acute hospitals, namely critical care areas (critical care units and emergency departments). The teaching hospital included the critical care areas were the purposive sample could be recruited. Due to data protection, a third party was used to help distribute recruitment posters, participant information sheets and invitation letters around the critical care areas. Additionally, the third party provided contact details for potential participants who expressed interest in the study. Gaining access was supported by the use of the third party because they were able to overcome many of the initial barriers of gaining access to the research site. As discussed above, ethical consent was gained from NHS Blood and Transplant to work with the third party [Specialist Nurse – Organ Donation] (please see ethical approval letter located in Appendix 4). Denzin and Lincoln (2008) discuss the

importance of establishing reciprocal relationships with stakeholders to help remove potential obstructions when gaining access to the sample site. Once the study had gained ethical approval from the specific hospital trust, appointments were made with the Lead Nurse and Clinical Director so that I could introduce myself and outline the study aims and objectives. Moreover, without agreement from heads of departments, a lone researcher wandering on to a critical care area would arouse suspicion and safeguarding issues (The Code NMC, 2015). Consequently, establishing professional relationships with key stakeholders and the third party support was important prior to the data collection process, to enable the safe and effective extraction of data from critical care staff.

The sample site consisted of 18 critical care beds where patients are supported on a mechanical ventilator (breathing machine). Care is provided by 22 critical care Consultants, 24 doctors in training (Specialist Registrars), 2 critical care matrons and 220 critical care trained nurses. This profile provides evidence that there is a significant number of staff to consider for recruitment to the study. However, as discussed above, the sample size is often small in qualitative research as the intention of participant recruitment is to focus on information rich data (Silverman, 2005; Charmaz, 2006).

3.11 Sample Characteristics

A defining characteristic of constructivist grounded theory is the importance placed on the participants of the study and the co-construction of social reality (Charmaz, 2006; 2014). Constructivist grounded theorists believe that *meaning* is a social construction, both the researcher and research participant interpret meaning and action (Bryant and Charmaz, 2008).

The critical care staff members interviewed were a mixture of registered nurses and medical doctors, 6 registered nurses (N = 6) and 2 medical doctors (N = 2). Following an expression of interest, the third party support offered each recruit a participation information sheet and an invitation letter. Three males and five females were invited for interview, 6 members of staff worked on the critical care unit and 2 members of staff worked on the emergency department. The sample consisted of a diverse range of professional experience and clinical grades from a newly qualified staff nurse to experienced critical care consultants.

The following section provides details of each participant, allowing insight into their experiences as health care professionals and to enable the co-construction of social reality with each participant (Charmaz, 2014). Ontologically, these reflective accounts are appropriate as the constructivist approach which underpins this grounded theory study places a priority on the sharing of experiences between the researcher and participants (Charmaz, 2006; 1990; Charmaz and Mitchell, 1996). As discussed above in this Chapter, each participant either selected or was allocated a pseudonym to maintain confidentiality and protect identity.

Jenny

Jenny was the first person I interviewed, having been identified by the third party support (resident specialist nurse – organ donation) who worked at the hospital. Following her participant information sheet and invitation letter, Jenny made contact through email wanting to take part in the study. She has been qualified for 18 months and describes being “thrown in at the deep end” with her role as a staff nurse on the intensive care unit. This was an intriguing statement and I wondered whether this experience, as described by Jenny, affects decisions made by relatives / carers regarding organ donation. Following our discussion, it

seemed to me that the demands of a new role and professional inexperience might influence donation outcomes.

Jenny had three experiences of organ donation from patients in her care, one very recently. She describes them as “bit emotional and sad”. She also reports some confusion with the plan to withdraw life sustaining treatment, stating they withdrew at the wrong point. As we started to talk, it is clear that Jenny had personal concerns about relatives / carers witnessing brainstem death tests. I am unsure if this was a lack of knowledge or whether she just wanted to protect the family from any additional harm. She described the brain stem death tests as “quite invasive”.

Jenny had no issues or concerns with organ donation as a concept but it is clear the ‘preamble’ regarding the diagnosis of death and withdrawal of treatment was a little more complex for her. She said the specialist nurse team provided a good service but she didn’t like the idea of referrals being made without the knowledge of the relatives.

Martin

Martin was the second person I interviewed for the study, recruited by the researcher following a chance meeting on the critical care unit. He had worked as a nurse on ICU for 10 years, climbing to the position of senior charge nurse. His demeanour was very calm throughout the interview and he thought carefully about answers before speaking. He did not have any concerns about relatives / carers witnessing brain stem death tests but said they would need appropriate support. He did express his view that following death it’s “like we start taking their body away from them”. I don’t think this was a negative statement, rather an expression of his concern for the grieving family.

Martin did mention a few times about people's belief systems interfering with clinical decisions. He was clear that personal beliefs should not be allowed to impact on clinical decisions. His own personal medical condition was discussed and he laboured over answering whether he would accept a lifesaving transplant. Whilst he said he would for his wife and family, he said having somebody's organ transplanted to his body would have profound psychological impact. I think this is a very honest answer to a very personal question but he was very supportive of organ donation in general. Martin did mention that it felt secretive when referring a patient to the on call specialist nurse – organ donation without the relative / carer knowing.

Kellie

Kellie was the third person I recruited for the study. Her role was as senior sister / practice educator, having worked in ICU for 20 years. Kellie mentioned that she came to this hospital from a neuro-surgical critical care unit, organ donation being a regular occurrence. Similarly to Jenny and Martin, she mentioned that personal and religious beliefs can affect clinical judgement and attitude.

Kellie talked openly about her experience as a student nurse. She said she witnessed an organ retrieval operation as a student nurse and it upset her a great deal. She described the event as traumatic, still affecting her now, regarding how the body appeared in theatre (Kellie was asked if she was okay to continue with the interview to which she said yes). She was interesting because this experience has not impacted on her support for organ donation. She believes the decision should be made by the relative / carer and that everyone should be asked. Kellie was informed that if she had ongoing and unresolved issues from her previous experience, professional support and help would be made available.

Thomas

Thomas was the fourth person I interviewed and worked as a consultant in emergency medicine and intensive care. He was recruited following an email I sent with information about study. He responded expressing his interest and desire to take part. Thomas had worked in a few different hospitals during his registrar training programme and has been a doctor for 21 years. He talked about how things have changed over that time, technology and practices, and said organ donation was just not on the radar back then. He did not have any concerns about relatives / carers witnessing brain stem death but said the language used at the bedside at this time is significant. He mentioned being familiar with the Neuro Linguistic Programme (NLP), which he said is essentially altering language / tone of voice to achieve certain desired outcomes or responses.

Thomas talked about professional experience and competence being important and that a newly qualified staff nurse might not be the most appropriate professional to deal with the demands of the organ donation process and grieving family. I read this to mean he was thinking of the welfare of the nurse at the bedside and how he / she can be best supported.

Thomas had no issues with the referral process and said all aspects of care in critical care are done in the best interest of the patient, including the referral to the on call specialist nurse – organ donation.

Carlos

Carlos was the fifth person I interviewed and worked as a consultant in emergency medicine and intensive care. He was an experienced professional having been a consultant for many years. The interview was conducted in an outdoor location at his request. Carlos was quick to

mention a family friend who had received a heart transplant. During visits to the swimming pool with his children, they would meet the heart transplant recipient. He described this experience as bringing “organ donation to life”.

Carlos mentioned that the changes that had taken place regarding organ donation were at an “unrelenting pace”. He talked about his frustration with the referral process for tissue donation, stating it was a prolonged endeavour when the department was busy. Carlos had undertaken further training with his professional colleagues and attended various organ donation workshops to enhance his own personal knowledge. Additionally, Carlos said that attaching statistics and key performance indicators to the subject of organ donation was flawed. He did not like the fact that you produce a statistic following the death of a patient and have targets and league tables set on how many organ donations the hospital has. Despite this criticism, Carlos expressed his commitment to promoting organ donation and found the referral process straight forward and the SNOD’s supportive.

Virginia

Virginia was the sixth person I interviewed and was eager to support the study. She had been qualified as a nurse for 10 months and explained she was due to start her extended critical care course in the near future. She described the critical care unit as busy but very supportive.

Virginia did not want to be interviewed on the hospital site. She was more comfortable travelling to my place of work for the taped interview. I recall asking her about that decision and she said she felt she could not talk openly on the hospital site.

She was very relaxed during interview and recalled her recent experience of organ donation and the grief of the family. She reported feeling ill equipped to deal with the enormity of the

organ donation process and demands of the grieving family. She reported returning home feeling “exhausted and teary” following the experience of organ donation from a patient in her care. She said that although the experience had affected her, she didn’t need any further help or support.

Virginia insisted that organ donation was a positive outcome for the family and that the specialist nurse – organ donation was supportive during the organ donation process. Her greatest concern, in my opinion, was her assumed lack of knowledge and competence but I found her to be wholly professional and caring. Her closing remarks were that all health care professionals should support organ donation and receive mandatory training to support their role.

Pink

Pink was an experienced critical care nurse who worked as a sister with the education team. Her initial nursing qualification was obtained outside of the United Kingdom but her degree was gained from a local university. Pink talked openly about her Hindu faith and how she had talked about her organ donation wishes with family. During the interview, Pink said she didn’t always agree with the decision to withdraw life-sustaining treatment and that more time should be afforded for some patients. The most striking note following my meeting with Pink was her description of the emotional impact on nurses relating to end of life care and organ donation. She described these situations as demanding and challenging, particularly affecting newly qualified and inexperienced colleagues. She also commented that relatives witnessing brain stem death testing should be an individual choice and offered routinely.

Her final commentary centred on the grief and bereavement as experienced by relatives. Pink was careful to articulate her point at this junction but stated that some families may be so grief stricken that they would not be “in the frame of mind” to engage in donation conversations. Pink suggested that technical language would most certainly influence decisions and that discussion regarding organ donation should be a multi-disciplinary approach.

Betty

Betty had been a critical care nurse for six and half years, starting as a newly qualified nurse within the critical care environment. She knew exactly how many times she had encountered organ donation or supported colleagues with the organ donation process. The number was 3 organ donations that she had dealt with directly and a further 2 when she had supported colleagues. Betty reported that she had observed a number of post mortem examinations which had supported her own education and development. She didn't view this as macabre in any way and said, in an organ donation context relating to her own organs, “I don't need them when I've gone”.

A significant note from my meeting with Betty was her concern relating to the timing of the donation request. She reflected on her own nursing practice and talked about honesty, integrity and transparency with end of life care. Towards the end of our discussion, Betty said she cannot recall any time where a doctor had made the referral for organ donation. She talked about the “clinical gaze” of some clinicians and that the medical model might perceive organ donation as a failure.

3.12 Chapter Summary

This chapter has presented the methodological approach that has been selected to answer the original research question. I have outlined the research paradigm with an emphasis on constructivist grounded theory. Both traditional and constructivist grounded theory have been discussed and critiqued. In addition, the philosophical components of grounded theory were presented which allowed me to position myself in the research. This chapter culminated in the identification of several key aspects which influence the research process including sample selection, sample size, gaining access to the sample, data collection method and objectivity.

Chapter 4: Data Analysis

4.1 Introduction

As outlined in Chapter 3, the constructivist grounded theory approach underpinning the research design positions the researcher as the interpreter of data (Charmaz, 2014). The interpretative tradition focuses not only on the *reality* of the social world, but also on people's interpretations of it (Green and Thorogood, 2014). This chapter presents a discussion concerning analytical methods that were influenced by Charmaz (2006; 2014). The analytical process helped to produce the grounded theory.

The interview process produced extensive data and it became challenging to recognise which data elements were important. Silverman (2006) argues that in order to make data analysis effective, it is crucial to have a limited body of data to work with, hence the proliferation of data collected required sorting. Tjora (2006) agrees that researchers must use their tacit professional knowledge to provide filtration regarding the detection of significant data from larger volumes of data.

It is acknowledged that qualitative data analysis presents deeper complexities than quantitative data analysis processes, primarily because analysing qualitative data relies on individual conclusions and interpretations of the researcher (Moule and Goodman, 2014; Bryant and Charmaz, 2007; Silverman, 2006; Grbich, 1999). There are significant challenges facing the researcher when analysing qualitative data including the effort required in the analysis of lengthy interview narrative and how the data can be translated into meaning and value (Polit and Beck, 2012).

However, adopting an analytical framework, as advised by Charmaz (2006; 2014), enables interpretation of the data through a rigorous approach. Furthermore, analysis of qualitative data ought to be embedded within the actual research process, often occurring during the data collection phase (Charmaz, 2014; Moule and Goodman, 2014; Bradley *et al*, 2007).

Qualitative data coding, the action of defining what the data represents, is the first analytical step (Charmaz, 2006). Essentially, coding means the labelling of sections of data that simultaneously categorizes, summarizes and accounts for each component of data (Charmaz, 2014; Bryant and Charmaz, 2007; Charmaz, 2006). Following the lengthy process of interview transcription, coding is the first step beyond the extensive narrative, allowing analytical interpretations. Qualitative coding dissects the data, making it easier for the researcher to develop abstract ideas from each data segment (Bradley *et al*, 2007; Mills *et al*, 2006; Eaves, 2001).

4.2 Line by line *in-vivo* coding

The first step in the analytical process was line by line *in-vivo* coding from the interview transcriptions. During this initial coding process, the interview transcripts were read thoroughly and key phrases and *in-vivo* codes from each participant were underlined. Similarly to Charmaz (2014), Corbin and Strauss (2008) support reading and re-reading of raw data to elicit meaning. The key words and phrases were written in a separate column on the right hand side of the transcript as outlined in Figure 4.1 on the next page. The use of Word 2010 track changes enabled the construction of comments regarding links and common themes in the data. The inaugural step of *in-vivo* coding captured the essence of what the participant has shared during the interview (Creswell, 2009). This was particularly useful as

in-vivo codes provided a meaningful insight into the experiences of critical care staff (Rintala *et al*, 2014).

Furthermore, *in-vivo* coding protected the meaning and action within the participant's narrative. The Word programme facility was a useful analytical process to identify action, connections and meaning within the transcription data set. For example, in Figure 4.1 below, formation of a nurse / patient relationship has been highlighted in green and yellow and is symbolic of an emerging initial code, which was identified on a number of occasions within the same data set. Equally, Green and Thorogood (2014) discuss the importance of being alert to *in-vivo* metaphors. Comparing and contrasting the metaphors used by people in their narrative can explicate underlying assumptions and open up paths of further enquiry.

Aligned with the epistemological views and ontological assumptions outlined in previous chapters, *in-vivo* codes are characteristics of the social world being investigated (Creswell, 2009). They reflect the experiences, views and opinions of the critical care staff which are framed within the actions and language of the narrative provided. Exploring these codes in more detail stimulated a greater appreciation of what is happening and what the words mean within each data set (Charmaz, 2006). Crucially, constant comparison of the initial codes allows the researcher to identify themes and commonality emerging from the data.

The following two data sets from the interview transcription provide an example of the initial coding and *in-vivo* coding phase of data analysis. The right hand column (initial code) is symbolic of key themes, ideas and actions that have been identified within the narrative (GB is the researcher).

Figure 4.1: Examples of Initial in-vivo coding from the interview transcriptions during which two in-vivo codes were identified (GB = Researcher).

Data set 1: Jenny	Initial code
<p>GB Can you recall those times Jenny Yes, each one, yes GB Go on just explain if you can Jenny So, first one was a patient who had a Catholic family 'humming and ah-ing' about organ donation but they decided to go for it. And then they didn't end up taking any organs from her, she didn't pass away. GB Right okay Jenny Second occasion was recently and they withdrew on a patient, they decided he wasn't for organ donation but he didn't end up passing away anyway. He's fine and gone to the ward GB Okay Jenny And then the third one GB Those two examples how did that make you feel that organ donation didn't proceed Jenny First one was a bit emotional side because I had to see the relatives again because it took a few days to pass away. Obviously they were quite reluctant about organ donation in the first place then they decided to go for it. I didn't really know what to say to her husband when I saw him again</p>	<p>Recalls each donation event</p> <p>Humming and ah-ing – <i>in vivo</i> code Faith / religion</p> <p>Decision making Sacrifice / protectionism Modification of word 'death'</p> <p>Withdrawal of care Decision on suitability Death / dying euphemism "passing away" Donation abandoned, patient improved</p> <p>Emotional experience</p> <p>Time / modification of word 'death' Initial apprehension / anxiety</p> <p>Decision making Challenging conversations</p>

Data set 2: Martin	Initial code
<p>GB And do you always agree with the decision to withdraw life support?</p> <p>Martin Erm.... I think I'm a great believer in, as I've become more experienced in ICU I've become more, how can I put it, I don't like seeing people suffering. We know the doctors here are very experienced and specialised, if they don't think</p> <p>Martin The normal process, like I said before, a relationship is formed unless it's an acute.</p> <p>GB How's it formed?</p> <p>Martin it is formed by a think we've got this policy / guidelines in place were the consultant and registrar have to make contact with the family within 24 hours. So it starts then with the medical team. With the nursing team, the bedside nurse starts to get to know the family, straight away we try an introduce we try and work with continuity of care , so the same nurse will go back to the patient and as you see the patient is deteriorating we always try as a nursing team to put the right nurse with the right patient who have got experience . Some nurses are better than others at dealing with things like this.</p>	<p>Experience Doing good / not causing harm Suffering Experience</p> <p>Normal process Professional relationship</p> <p>Policy guiding practice Timely Medics start first Relationship</p> <p>Continuity of care Consistent care</p> <p>Right patient with right nurse Experience, personal comfort levels</p>

The initial coding and in-vivo coding process revealed interesting points and commonality within the data. The two extracts above suggest that death and dying are complex issues for critical care staff. Equally, the initial data analysis suggests that some nurses might be better placed to deal with the emotional demands of a dying patient. Line by line analysis is an essential component on the journey to theory generation. Each word spoken by the participant

had the potential to bring out different aspects of the same phenomenon (Corbin and Strauss, 2008).

4.3 Constant Comparative Method

Richards (2010) labelled the constant comparative method as searching for “*similarities and differences by enacting a systematic comparison across units of data*” (p 58). The line by line analysis outlined above keeps the researcher *grounded* and focused on the data rather than imposed theoretical flights of fancy (Charmaz, 2006; Glaser, 1978; Strauss and Corbin, 1990). Equally, the constant comparison method encourages critical analysis of participant responses which allows the identification of common themes. The following sections illustrate how the constant comparative method was used throughout initial coding, focused coding and theoretical coding. For example, the constant comparison method detected modifications and euphemisms for the word “death” within the initial coding process, such as “passed away” and “passed”.

4.4 Abstract Situational Mapping

Coupled with “*theorizing*” as identified by Charmaz (2014), the use of an abstract situational map below (Figure 4.2) helped to identify connections with the codes and categories. An abstract situational map can be used to identify the major human, non-human, discursive and other elements in the data set. Moreover, abstract mapping encourages further data analysis and surveillance for links in the data (Clarke, 2003). Additionally, exploring “*who and what are in the situation*”, once the map was constructed, supported both the focused and theoretical coding process (Clarke, 2005; p 87). This active process and constant comparison

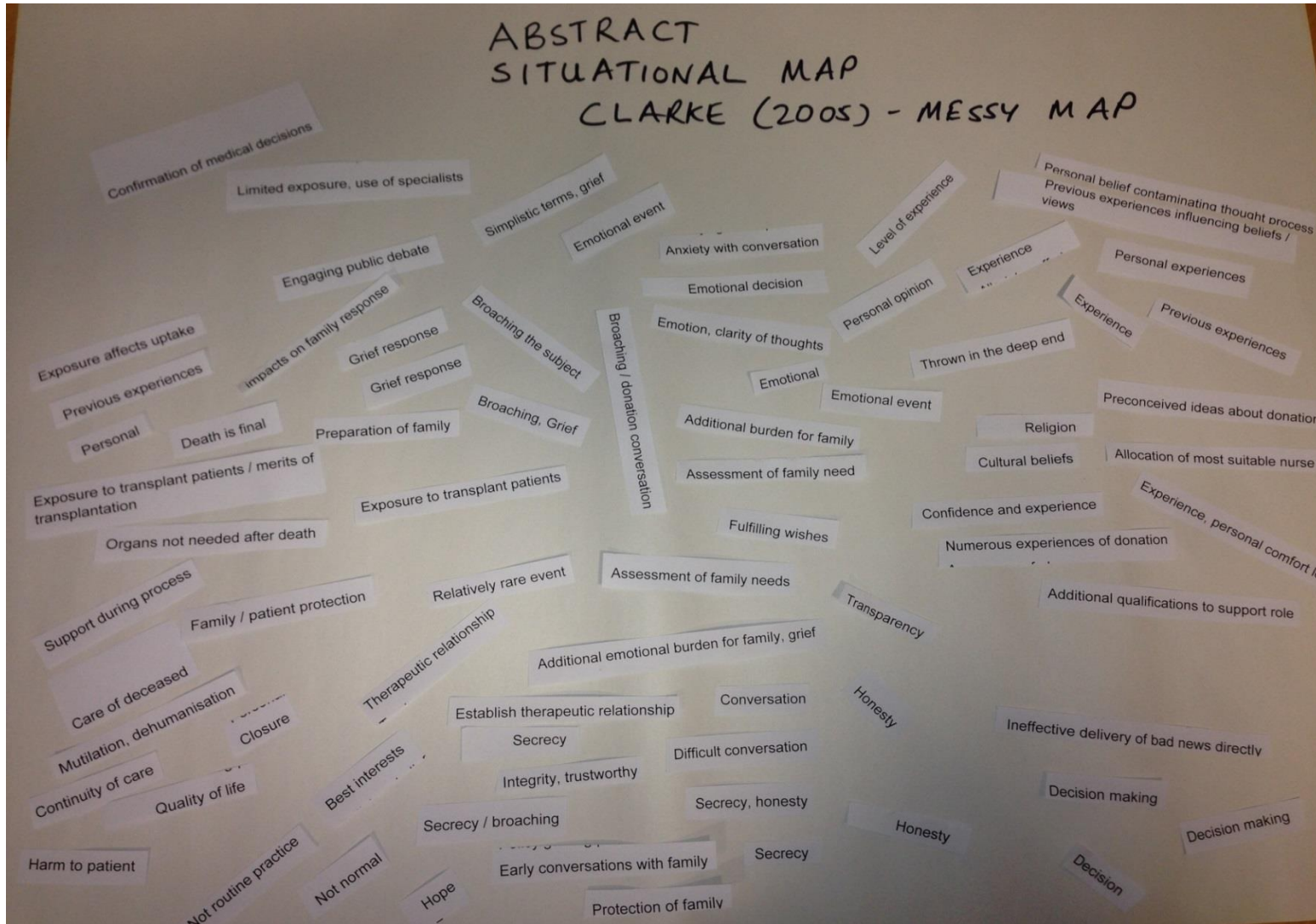
of data facilitated the development of early conceptual categories. All the initial *in-vivo* codes were cut and pasted on to a separate Word document and the font enlarged. Each data segment was then cut out and placed on to flip chart size paper (Figure 4.2).

As Clarke (2005) discusses, abstract situational maps appear “*very informal, often downright messy and seemingly disorganized*” (p 94). However, she argues that messy mapping is a perfectly legitimate way of working analytically. Consistent with the constructivist approach to my methodology, too much order provokes premature closure, a significant risk with grounded theory research (Charmaz, 2014; Clarke, 2005).

Working with the messy map provided a helicopter perspective which enabled the collating and merging of codes to form categories. Collapsing and expanding the potential categories was “*extraordinarily powerful*” and “*analytically provocative*” (Clarke, 2005; p 89).

Additionally, I kept written notes at the end of the map and these highlighted changes in my thought process, setting direction for theoretical sampling. The abstract situational map on the next page was based on the first six interviews.

Figure 4.2: Abstract Situational Map (Clarke, 2005)



4.5 Theoretical Coding

An advanced stage of grounded theory coding is known as theoretical coding which involves moving “*your analytical story in a theoretical direction*” (Charmaz, 2014; p 150).

Theoretical codes provide the foundation for the abstract early coding to be deciphered in to a powerful storyline and generation of theory (Birks and Mills, 2015). However, Glaser (2005) reports this stage of coding is often the most challenging for the novice researcher.

Interestingly, some grounded theorists argue that theoretical coding is not an essential or integral part of theoretical development (Glaser and Holton, 2013). Conversely, Cutcliffe (2000) asserts that theoretical coding encourages a “*full and rich understanding*” of social processes and human interaction (p 1482).

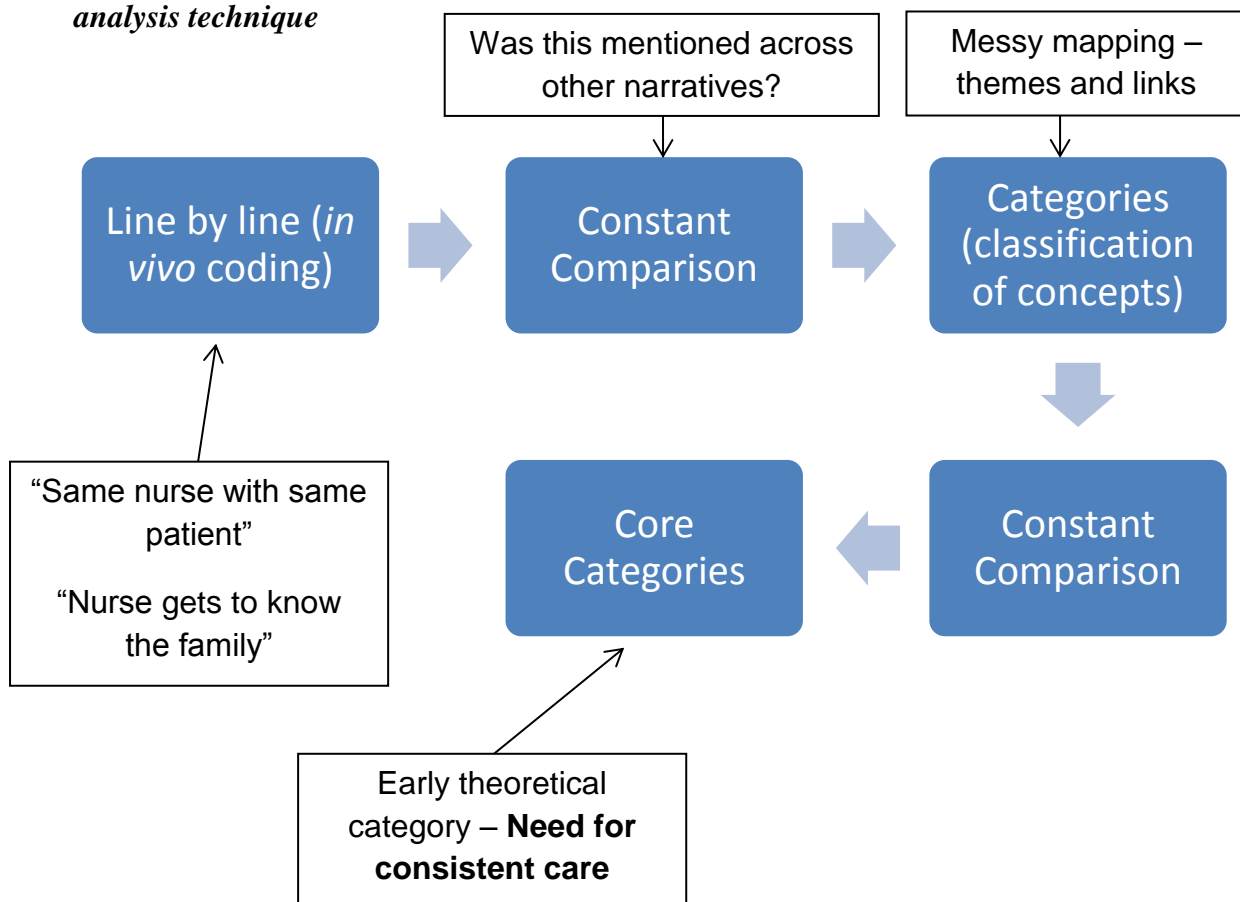
Essentially, theoretical coding was an opportunity to interrogate the sets of data for meaning.

The iterative process used within the study helped to generate theoretical codes that co-constructed a storyline (Birks and Mills, 2015). According to Birks and Mills (2015), the most effective way to achieve theoretical coding is through written discourse or visual modelling (usually both) when preparing the final theory. The use of an abstract situational map above (messy / working version) was useful to critically analyse the key human, non-human and symbolic elements following initial coding (Clarke, 2005). For example, an early theoretical code that emerged from the messing mapping process was the significance of professional experience.

4.6 Focused Coding

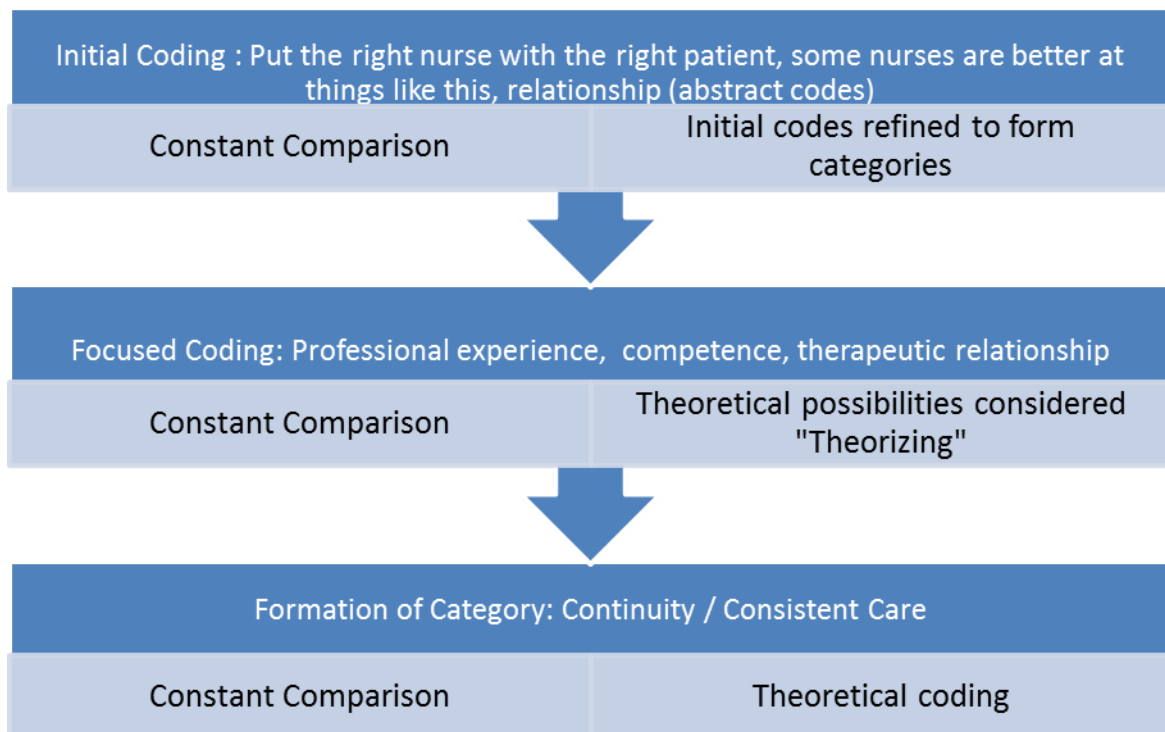
Following the extrapolation of initial codes from line by line analysis, the second major stage was focused coding. Focused coding means the selection of the most significant and/or frequent initial code to sift through larger volumes of data. As identified by Glaser (1978), these codes are more directed, selective and conceptual than line by line coding. The grouping together of similar initial codes and phrases created categories. Consequently, the categories are of a higher, more abstract order than the earlier codes (Charmaz, 2006; Strauss and Corbin, 1990). Embedded in the step of grouping concepts together to form categories was the constant comparative method (Figure 4.3). According to Charmaz (1983) and Strauss and Corbin (1990), a core category is the dominant theme of story line that emerges following data analysis.

Figure 4.3: Simplified diagrammatic representation of Charmaz's (1983) multi-step analysis technique



Consistent with a constructivist grounded theory approach to the study, coding was an iterative process throughout the research process (Appendix 13). As Charmaz (2006) states, grounded theory coding derives from the active engagement of the researcher in this iterative process. Focused coding allows the movement and inspection across interviews and compares people’s experiences, actions and interpretations. Figure 4.4 below identifies how codes and categories condense data and allow greater analytical control by the researcher. The example below demonstrates the active process during focused coding and resulted in the formation of three minor conceptual categories: ‘Professional Experience’ and ‘Competence’, ‘Beneficence’ and ‘Non-maleficence’ and ‘Therapeutic Relationship’. Focused coding, as an active process, was maintained in conjunction with theoretical coding until all theoretical categories had been exhausted (Figure 4.5).

Figure 4.4: Flow chart to depict formation of categories



The example below illustrates the progression from initial *in-vivo* coding to the development of conceptual categories. Furthermore, this stage of the coding process was used in conjunction with the abstract situational map (Figure 4.2).

Figure 4.5: Use of focused coding to support development of conceptual categories.

Interview with Martin	Initial Codes	Minor Conceptual Category
<p>GB And do you always agree with the decision to withdraw care?</p> <p>Martin Erm.... I think I'm a great believer in, as I've become more experienced in ICU I've become more, how can I put it, I don't like seeing people suffering. We know the doctors here are very experienced and specialised, if they don't think</p> <p>Martin The normal process, like I said before, a relationship is formed unless it's an acute.</p> <p>GB How's it formed?</p> <p>Martin it is formed by a think we've got this policy / guidelines in place where the consultant and registrar have to make contact with the family within 24 hours. So it starts then with the medical team. With the nursing team, the bedside nurse starts to get to know the family, straight away we try an introduce we try and work with continuity of care, so the same nurse will go back to the patient and as you see the patient is deteriorating we always try as a nursing team to put the right nurse with the right patient who have got experience. Some nurses are better than others at dealing with things like this.</p>	<p>Experience</p> <p>Suffering</p> <p>Experience</p> <p>Normal process Formation of professional relationship</p> <p>Policy guiding practice</p> <p>Timely Starts with medics</p> <p>Relationship</p> <p>Competence and Experience</p> <p>Experience, professional competence Experience, personal comfort levels</p>	<p>Professional Experience and Competence</p> <p>Competence and Experience</p> <p>Benevolence and Non-maleficence</p> <p>Therapeutic Relationship</p>

Early emerging concept: featured a few times – “right nurse with the right patient”

4.7 Axial coding

The grouping of codes within the initial coding stage lead to the formation of categories which, in turn, aided the growth of conceptual patterns during the analysis process (Birks and Mills, 2014). For example, under the core category the early emerging concept of ‘Continuity and Consistent Care’ is supported by subcategories of initial codes: “put the right nurse with the right patient”, “some nurses are better than others at dealing with things like this” and “same nurse will go back to the patient”. One of the key features of the coding process is the relationship between and integration of categories. Strauss and Corbin (1998) label this third stage of coding as axial coding, specifying the characteristics and properties of a category. However, Clarke (2005) views axial coding as an extension of a category and uses diagrams to highlight the constituents of categories. In contrast, Charmaz (2006) does not adopt the formal axial coding procedures according to Strauss and Corbin (1998). Instead, she developed subcategories and described the links between them as she gained knowledge of each core category (Charmaz, 2006). Therefore, the emerging conceptual categories are supported by a series of subcategory codes. Furthermore, the data analysis process was supported through the use of memos which strengthened ideas, themes and categories within the data set.

4.8 Memo writing

Bryant and Charmaz (2007) suggest that the starting point for memo writing occurs when the researcher has initial ideas and thoughts regarding the data. Memos encourage the researcher to look for links with the data and helps with the generation of theory. The analytical memos explicate underlying researcher assumptions regarding themes in the extracted data and are a “*private concern between the researcher and his (sic) data*” (Bryant and Charmaz, 2007;

Page 251). Equally, Clarke (2005) describes the use of memos as “*intellectual capital in the bank*” (p 85). Within grounded theory studies, memo writing is an iterative process and continues throughout the life cycle of a study (Birks and Mills, 2015). For example, the use of memos during the interview stage of the study was incredibly useful as it allowed me to map out possible sources to sample theoretically. As the interview questions evolved from one participant to the next due to theoretical possibilities, the use of memos provided an audit trail which defended decision making processes.

Memos are not just a mechanism to provide analytical insights, they act as a synergy between data analysis and theory generation. Revisiting memos through the constant comparative method unifies concepts and identifies relationships in the data (Corbin and Strauss, 2008). Charmaz (2014) advocates creativity during the memo comparison stage, offering practical advice. She suggests that memos are sorted by their associated category, arguing this helps to provide logical sequence to the studied phenomenon. Charmaz (2014) encourages the researcher to revisit memos periodically throughout the data analysis process.

As advised by Charmaz (2014), memos remained spontaneous throughout the research process. An example is the field memos I kept during the interviews, these memos were often short and written on the interview schedule (Figure 4.6). Equally, memo writing forces the novice researcher to interrogate processes, assumptions and actions within the data set. Grounded theorists inspect data for patterns and the memos help to preserve meaningful evidence within the data. This could be memoing a critical word or a series of verbatim material offered by the participant which helps to ground abstract ideas (Charmaz, 2014; Glaser and Strauss, 1967).

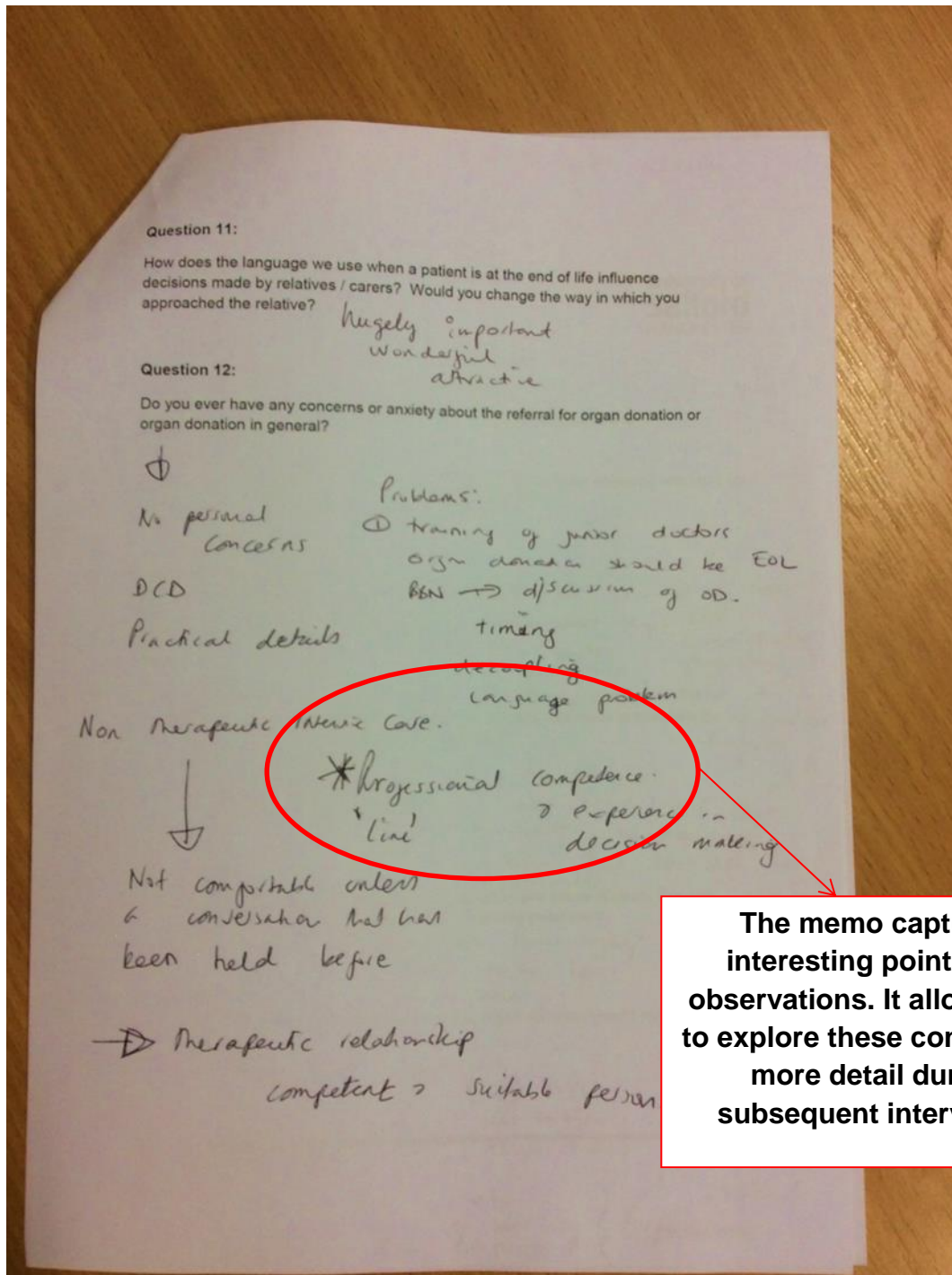
Birks and Mills (2014) suggest that the three elements necessary for the integration of a grounded theory include: an identified core category, theoretical saturation of major categories and an accumulative bank of analytical memos. Glaser (1978) designates memoing as “*the bedrock of theory generation*” (p 83). The example memo below, written following the interview with Martin, demonstrates how the use of memos supported the development of abstract concepts (Figure 4.6). Additionally, memo writing advanced abstract concepts to higher-level concepts, helping balance the studied experience, categories and emerging theoretical statements (Charmaz, 2006).

Memo 1: Exemplar memo written following the interview with Martin

Continuity of care and consistent care appear to be important considerations as the patient approaches end of life. The data indicates that putting “the right nurse with the right patient” and that “some nurses are better than others at dealing with things like this” are related to two important concepts. Firstly “the right nurse with the right patient” suggests that competence is an important issue. Secondly, “some nurses are better than others at dealing with things like this” suggests that some nurses are better equipped to deal with the demands of a dying patient. My initial assumption is that these concepts [continuity of care and consistent care] need further exploration to ascertain greater understanding. Martin stressed the importance of the bedside nurse getting to know the family and establishing a professional relationship. Further assessment is needed regarding these concepts.

In this example, the participant had talked about the skills involved in detecting a potential organ donor. This raised interesting points and new concepts to explore during future interviews.

Figure 4.6: Memos kept on the interview schedule.



The memo captured interesting points and observations. It allowed me to explore these concepts in more detail during subsequent interviews.

4.9 Theoretical sufficiency

Traditional grounded theorists assert that sampling should continue until all categories are theoretically saturated (Glaser, 1998; Glaser and Strauss, 1967). However, Dey (1999) denounces the concept of theoretical saturation with grounded theory studies for two reasons. Firstly, he describes the term theoretical saturation as an “*unfortunate metaphor*” (p 257), suggesting that saturation relies on the researcher’s speculation that the assets of each category are saturated. Secondly, Dey (1999) favours the term *theoretical sufficiency* and rather than having categories saturated by data, he argues categories should be *suggested* by data.

Dey’s (1999) argument complements the constructivist methodological approach adopted for this study. Rather than viewing saturation as a result of data generation, theoretical sufficiency becomes a modification of theoretical saturation as a rich source of textual analysis that encourages diversity of meaning. Furthermore, Dey (2007) contests that saturation should not be at the expense of category refinement. Data analysis in grounded theory remains a continuum until formation of the final theory, therefore theoretical saturation will not be fully achieved until completion of the study (Birks and Mills, 2014). The notion of theoretical saturation, in grounded theory, relates not merely to ‘no new ideas emerging from the data’ but to the notion of conceptually dense theoretical accounts from the field of interest (Green and Thorogood, 2014).

4.10 Chapter summary

This chapter provided a detailed overview of the data analysis process that was employed in the study. The data analysis guidance offered by Charmaz (2006) has been observed which supported the development of initial, focused, theoretical and axial codes. The importance of memo writing was discussed and how they support the advancing of abstract concepts. The chapter discussed how the saturation of theoretical concepts, as opposed to saturation of the sample, achieved theoretical sufficiency. Chapter 5 presents the findings from the study which was obtained from the methods used above.

Chapter 5: Findings and Discussion

“You know I think a lot of time when it's been something that's been quite sudden, quite unexpected and even if it isn't, even if it's somebody that struggled with a chronic condition for a long time, I think that sometimes families do think like why is this happening to me? Understandably, why has it happened to me and I know I have heard family say like you don't deserve this to the patient and it's so unfair and you don't deserve this. The thought then that they going to give consent to go through more after they have died, I think that that's too much for some families”.

Virginia [Staff Nurse]

5.1 Introduction

In this Chapter I present the findings from the analytical processes outlined in Chapter 4. The findings identified four theoretical categories which include ‘Secrecy’, relating to critical care staff concerns that the organ donation process is secretive, ‘Mutilation’, connected to the belief that the patient could be harmed following death, ‘Broaching’, concerned with critical care staff’s fear surrounding donation discussions and ‘Experiential Competence’ which encompasses critical care staff competence associated with organ donation. Examples of the selective coding process, use of abstract situational maps (Messy Maps) and memo writing are integrated to ensure transparency during the development of each theoretical category. Finally, the core category, entitled ‘*Fear*’ is defined, which leads to the construction of a conceptual framework. The findings are discussed using contemporary literature and theoretical perspectives, exploring the way in which *Fear* impacts on the social interactions and perceptions of critical care professionals.

During the interviews, I observed numerous examples of ‘protective’ nursing care when a patient is dying. As the quotation by Virginia in the epigraph indicates, and the data analysis process revealed, critical care is grounded on the principle of harm free care. Based on the findings from the analytical process, I argue that *Fear* is a recurring phenomenon shared by

critical care practitioners when caring for dying patients and their relatives / carers. Mira (1939) suggests:

"At the basis of normal fear and in particular of pathological fears there lies a predominance of the physiological process of inhibition"

(p 1395)

I propose that 'inhibition' can be applied to critical care professionals who are fearful of the donation process. Mira (1939) also suggests that uncontrolled fear, in severe cases, makes a person "terrified". That is to argue that I do not feel it appropriate to label critical care staff as 'terrified' of organ donation, rather that *fear* attributed to each aspect of the donation process 'inhibits' successful outcome. It was clear to me that I was witnessing unhelpful strategies from nurses and doctors to cope with the demands of organ donation from dying patients. These concepts will be discussed more fully within the discussion of each theoretical category.

5.2 Theoretical Category 1: Secrecy

The analytical process revealed that ‘Secrecy’ was a predominant feature of critical care staff experiences of organ donation. ‘Secrecy’, in this context, relates to two separate issues connected to the donation process. Firstly, critical care staff reported concern with the referral taking place to assess suitability to donate without knowledge of the relative / carer. Secondly, critical care staff appeared to have anxiety with the attendance of the on call Specialist Nurse – Organ Donation who might not initially introduce themselves to relatives with their full professional title. Gaining understanding of this theoretical category enabled higher level assumptions into how ‘Secrecy’ influences experiences and perceptions (Grbich, 2013). In addition, memo writing was used to enhance the theoretical category in relation to the study findings (Holton and Walsh, 2017). The abstract situational map ‘Messy Map’ I used to develop the theoretical category is presented in Figure 5.1. To illustrate this, an excerpt was taken from the interview with Jenny and introduces the concept of ‘Secrecy’. Jenny had been asked to describe what happens when a patient is referred to the on call Specialist Nurse – Organ Donation. Certain words in the following excerpts are highlighted in yellow which illustrates how selective coding helped to form the theoretical category.

Excerpt 1:

“No I think they are a very good team, like I said they are very supportive with us and the family. Sometimes I find it a bit difficult when the subject has not been broached with the family but then we’re talking to the organ donation team. Like prior to broaching the subject, it’s sort of a bit secretive but again I understand that because the subject has not been broached”.

Jenny [Staff Nurse]

Jenny, who was a newly qualified staff nurse, stated that the donation process is not transparent and that conversations take place without knowledge of the relative / carer. In particular, Jenny mentioned to the referral process to the specialist nurse – organ donation as secretive. Within Excerpt 1, Jenny stated she finds it difficult to hold discussions with specialist teams regarding suitability for donation without knowledge of the relative / carer. The analytical process prompted me to reflect on the interview with Jenny and prompted the following memo (Memo 2).

Memo 2:

The interview data revealed that Jenny has some sort of difficulty with having conversations with the SNOD without prior knowledge of the family. This could have the potential to influence her comfort / discomfort with the organ donation. Furthermore, Jenny discussed the fact that the specialist nurse – organ donation would then attend to assess suitability and “the family haven’t got a clue who that person is, were we know it’s the organ donation team”. This requires investigation. Jenny’s description and experience of referring a dying patient for organ donation was intriguing and influenced my decision to explore this further.

In her book *Secrets*, Bok (1989) states that “*anything can be a secret so long as it is kept intentionally hidden*” (p 5). Interestingly, her debate matures to explore why the keeper of the *secret* is keeping it concealed. Likewise, the referral of a dying patient to the on call SNOD to assess donation suitability is often concealed from the relative / carer. I agree with Bok, there is a significant difference between keeping a secret and telling a lie. Secrecy refers to the resulting concealment and lying is characterised by the telling of untruths (Bok, 1989).

Jenny's interview exposed a *fear* that the family might overhear conversations about the potential for organ donation. For example, Jenny reported unease with referring to the duty SNOD with the knowledge that the relative might overhear. As the constant comparison method developed, 'Secrecy' was detected as a common concern for the study participants. This appeared to suggest that 'Secrecy' within nursing practice causes detrimental harm to the relationship between patients and their relatives. Across five of the narratives (Jenny, Martin, Kelly, Virginia and Pink), 'Secrecy' was mentioned and the following excerpts present the foundation of this theoretical category. Excerpt 2 was taken from the interview with Martin who had been asked about how he feels when the Specialist Nurse – Organ Donation (SNOD) attends to assess suitability of the patient for donation.

Excerpt 2:

*"It's almost looks like it **becomes secret then**, what are they doing in there type of thing".*

Martin [Senior Charge Nurse]

Following the interviews with Jenny and Martin, Kellie was asked about her thoughts of the SNOD being contacted when a patient is dying.

Excerpt 3:

*"You have to talk to them, you have to address the issue, sort of like bring it up and talk about it openly, not as in a **secretive thing**. It's got to be there, it's got to be present. It's not to come as a shock. I've got all this emotional thing going on and now you are asking me this".*

Kellie [Senior Sister]

Table 5.1 demonstrates how selective coding (words highlighted in yellow), as advised by Charmaz (2006), helped to explicate ‘Secrecy’ as a theoretical category.

Table 5.1: Selective codes used in excerpts 1, 2 and 3 which supported ‘Secrecy’ as a theoretical category.

Participant	Selective Code	Theoretical Category
Jenny	it's sort of a bit secretive	Secrecy
Martin	becomes secret then	
Kellie	secretive thing	

In contrast, the interview with Virginia introduces a different perspective related to *openness* which I believe is in stark contrast to Secrecy. Virginia was asked about the skills needed when communicating with a grieving family. This encouraged me to write a reflective memo (Memo 3) and inspect the field note I had written during the interview Figure 5.2.

Excerpt 4:

“Well I don't know it's um, it's really hard to define thing because sometimes you just don't know how, this family, I had a really good relationship with them and when I think about it, I really don't know what makes it what it is. It's really hard to put into words isn't it. I think when you've got that openness, I think that when at end of life my main aim is when providing end of life care is once the patient were you're probably not having verbal communication anymore it's with the family. You know there has been so much bad press in the past about end of life care and how it can go really wrong, how families can feel”

Virginia [Staff Nurse]

Memo 3:

The interview with Virginia suggests 'openness' as an important ingredient for a therapeutic relationship. The previous interviews have alluded to the concept of secrecy. In contrast, Virginia has talked about 'openness' with the family which would be compromised to a secretive referral to the on call specialist nurse – organ donation. This field note below highlights that openness was important to Virginia, highlighted with an exclamation mark. Although secrecy was not mentioned directly, it is my feeling that openness is an important nursing value. This made me think of my professional experiences as a critical care nurse. I reflected on what being 'open' means and concluded that 'Openness' is fundamental to care provided on critical care. Somehow withholding information just appears wrong.

Figure 5.2: Field note of interview with Virginia

②
Minesfield
Assess family decisions.
Keep the concepts
Therapeutic relationship
apartness! Explaining
Scary "dehumanising"
legacy. or
talked with passion.
communication with NOT.
Struggle feel like have ↑ on
family
to know more than family 'awful'
Guilty with knowledge
* BSD family witnessing
→ family choice
NOT relaying info 2nd hand.
Shared experience with family.
Previous experiences!!!
Putting patient through more

Virginia talks about the importance of “openness” and the challenges of communicating with a dying patient. Virginia appeared to be uncomfortable with the concealment of secrets. Following the first six interviews, a messy mapping exercise, as advised by Clarke (2005) was conducted, and helped to establish ‘Secrecy’ as a theoretical category. Responses from the first six participants were cut out and placed on flip chart paper which, according to Morse, helped with the identification of links in the data (Morse *et al*, 2009). The messy mapping process provided a platform to test ‘secrecy’ as a theoretical category on the final two participants. Initiating a labelling system for the emerging data offered me an opportunity to retain data-memo connections and audit trail for thesis defence (Charmaz, 2014; Holton and Walsh, 2017). Pink, the seventh participant to be interviewed, was asked what her thoughts are regarding the referral of a dying patient to the on call SNOD.

Excerpt 15:

“Yeah, first of all it's very difficult for the organ donation topic to come up when the family is grieving, it's absolutely difficult. Because they are already grieving for their loved one, who they are losing, you go and talk to them about this they are not in that frame of mind to take it in. It is very uncomfortable for us when somebody [SNOD] is at the bedside reading through notes, it is very secretive. Erm, they are not prepared for that conversation it makes it very difficult”.

Pink [Sister]

The narrative in excerpt 15 indicates that Pink has difficulty in keeping secrets from relatives. Moreover, Pink was uneasy about the SNOD attending the referring unit and examining patient notes without knowledge of the relative / carer. In addition to the context of critical care staff keeping secrets, the guiding biomedical ethic of *non-maleficence* appears to be the trigger for concealment of the secret (Beauchamp and Childress, 2013). On the occasions I refer to above regarding secrecy, the ‘*primum non nocere*’ [above all do no harm] appears to

influence practice. Findings indicate that critical care staff *fear* disclosing the fact that a patient has been referred to the on call SNOD because this knowledge may cause harm to a relative / carer. However, this practice and concealment of such a secret is without any detectable evidence base and testing whether transparency and honesty with relatives / carers, in this context, remains unexplored. I have argued that some critical care doctors and nurses have discomfort with keeping secrets from relatives. Thus, it is important to explore the literature and discuss how the *fear* of revealing secrets affects therapeutic relationships.

I now concur with Gadow and suggest that the concealment of secrets inhibits productive *narrative* and “*good that is being sought*” by the relative and nurse (Gadow, 1996; p 8).

Equally, Olthuis *et al*, (2006) argue that quality communication with a dying patient depends on humanistic and egalitarian relationship with nurses. However, I suggest that person centred care cannot be achieved in a patient declared brainstem dead, therefore meaningful partnership between the nurse and patient is impossible. Fredriksson and Eriksson (2003) propose that the foundation for ethical caring conversations between the nurse and patient includes ‘*autonomy*’ and ‘*reciprocity*’ (p 138). I have argued in Chapter 1 that when the patient lacks autonomy, the nurse becomes “*protector of humanity*” (Griffin, 1983: p 291). Thus, it is reasonable to suggest that the nurse, in the context of keeping secrets from a patient who lacks autonomy, is unable to alleviate suffering through caring conversations (Olthuis *et al*, 2006).

Moreover, the French philosopher Ricoeur (1995) argues the ‘good’ (ethics) has primacy over the ‘obligatory’ (morality). In an organ donation context, the willingness of the nurse to do ‘good’ and not withhold secrets competes with the ‘obligatory’ duty to refer dying patients for organ donation. Skott (2003) explores the dilemma of autonomy and caring conversations, suggesting that:

“To do what is right and good for someone requires that one has reliable understanding of what is best for the person in moments of choice”

(p 368).

In a similar way, Neilen (2013) argues that the biomedical principle of autonomy means nothing when it is separated from the person it is meant to protect and benefit. Furthermore, Neilsen (2013) contests that autonomy is mostly concerned with informing the patient about treatment. I agree with the writing of Neilsen and that the real issue is *informed* consent.

“Informed consent means having real and sustained conversations with patients. Informed consent means that physicians and other health care professionals are informed about their patients, their lives, their dreams, and their hopes. It is, in other words, a two way process and document. Autonomy means very little if the decision I am being asked to make has not been fully explained to me”

(Neilsen 2013; p 11).

I have reflected on the quotation above and the final sentence captures the inherent tension experienced by some critical care professionals when referring dying patients for organ donation. A patient who lacks capacity, due to critical illness, is unable to verbalise wishes or make an informed decision about referral to the on call specialist nurse – organ donation. Establishing expressed wishes relating to organ donation is advocated by the Human Tissue Act (2004); however it is known that only 30-44% [regional variation] of the UK population is active on the Organ Donor Register (ODR) (NHSBT, 2017; Appendix 3). That is to argue that nearly 56-70% of people in the UK have not opted-in and made their wishes explicit regarding organ donation. It appears that keeping secrets, especially when the patient is unable to make autonomous decisions, generates anxiety and fear amongst some critical care doctors and nurses.

A study by Ochieng *et al*, (2015) highlights the importance of medical and nursing professionals gaining informed consent from patients prior to surgical procedures. A dying patient in ICU / ED is referred to the on call specialist nurse – organ donation (SNOD) to

ascertain suitability for organ donation. Organ donation is only possible through a surgical procedure known as the organ retrieval operation. Their study concluded that majority of patients insisted that doctors explain procedures prior to surgery. Furthermore, the study suggests that communication could be improved by doctors providing a “*detailed explanation*” but this is not possible when the patient is certified brainstem dead (Ochieng *et al*, 2015; p 1).

The function of critical care is to intervene and postpone death by the use of advanced technology to support organ dysfunction (Dobb *et al*, 2016; Burns, 2015). Through systematic assessment, the critical care nurse develops a care plan with a primary focus on improving health and saving life. However, 529,655 deaths were registered in England and Wales during 2015, 22,200 of these deaths occurring in critical care (ONS, 2016; ICNARC, 2016). Consequently, the critical care team inevitably have to engage with the concept of death and dying. Critical care appears to be predicated on saving and prolonging life but there is little discussion on the transition from saving to end of life care (Coombs *et al*, 2012). In contrast, *non-maleficence*, one of four biomedical principles highlighted by Beauchamp and Childress (1995; 2013), stipulates that nurses have an ethical duty to promote wellbeing but also recognise whether the treatment is an excessive burden.

This is linked to autonomy and the patient’s right to make a decision but, as discussed above, doctors and nurses appear unable to lift from a “*clinical gaze*” and enact the role of “*protector of humanity*” (Hall and Ritchie, 2013; Griffin, 1983; Jewson 1976; p 229). The medical ideal of saving life, at all costs, with the resources available conflicts with the awareness that prolonging is useless and unduly painful, the ideal often wins out (Glaser and Strauss, 1965). Nurses are placed in challenging situations as their awareness of futility and “*nothing more we can do*” attitude competes with the “*prolonging*” medical philosophy of university affiliated hospital doctors (Glaser and Strauss, 1965; p 201).

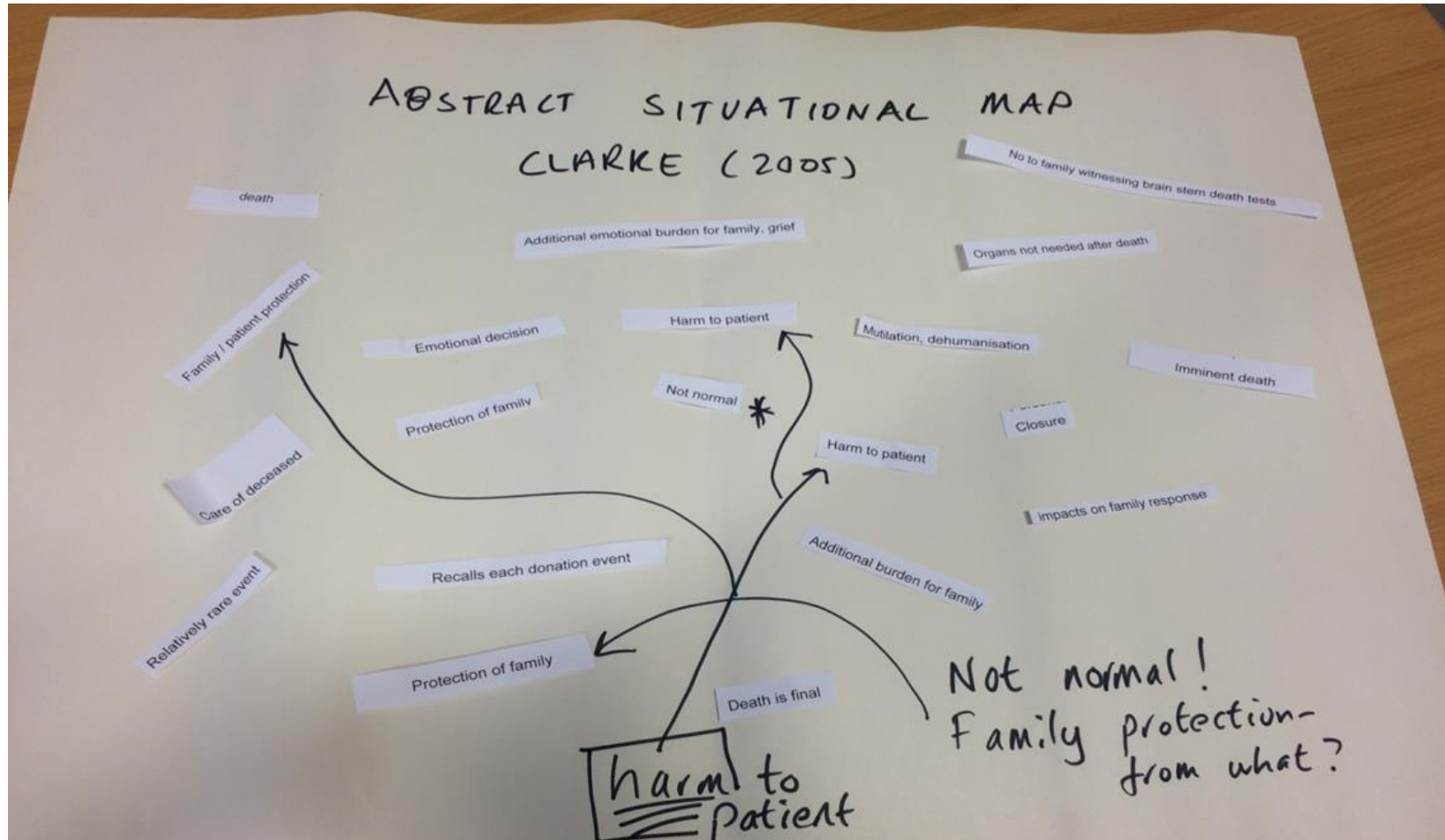
Finally, I discuss the practice of the on call specialist nurse – organ donation attending the referring critical care unit to examine the medical notes of the dying patient. Participants reported discomfort with the SNOD being “*at the bedside reading through notes, it is very secretive*” (Jenny). Guidance issued by the British Medical Association (BMA) and Nursing and Midwifery Council (NMC) state that practitioners have an ethical obligation to respect patients’ confidentiality, even beyond death. Within section 5 of the *Access to Health Records* (BMA, 2014), no mention is made of organ donation professionals accessing a deceased persons medical notes for the purpose of donor screening. That is not to suggest that the practice of the SNOD reading medical notes following the death of a patient is unlawful, more that the guidance is not transparent. In this context, it is reasonable to assume that critical care professionals *fear* litigation when allowing other professionals access to health records of the deceased.

5.3 Theoretical Category 2: Mutilation

The fear of the deceased body being mutilated is identified as the second theoretical category following data analysis. The findings suggest, supported by the analytical process, that the fear of the body being mutilated following death affects critical care staff relationship with organ donation. Additionally, this belief is consistent with the work of Verble and Worth (1999) who reported that the fear of mutilation is a significant barrier to organ transplantation. Moreover, Verble and Worth (1999) suggest that the fear of mutilation is a form of “mystical thinking” and a representation of blood phobia, therefore not open to conventional education initiatives. In a similar way, television and media reports inform people of the donation process, and this is often conveyed as insensitive and barbaric. A British Broadcasting Corporation (BBC) series of *Holby City* screened in 2013 received 48 letters of complaint following its portrayal of organ donation. The programme was regarded as “reckless”, prompting people to remove themselves from the organ donor register (NHSBT, 2013). This is significant as the media perception and portrayal of organ donation influenced my analysis of the data.

Interestingly, as discussed in Chapter 2, Sque *et al* (2007) used the terms ‘sacrifice’ and ‘gift of life’ when exploring why relatives do not donate organs for use in transplant operations. They concluded that the traditional message attached to organ donation as the ‘gift of life’ failed to acknowledge relatives concerns, arguing that ‘sacrifice’ might be a more powerful construct. The term ‘Mutilation’ has an equally powerful construct which captures the tension faced by participants when facing the potential for organ donation. The abstract situational map ‘Messy Map’ that I used to develop the theoretical category is observed below in Figure 5.3.

Figure 5.3: Abstract Situation Map 'Messy Mapping' (Clarke, 2005)



Kellie was talking about her experiences of witnessing organ donation as a student nurse.

Excerpt 16:

“I was a student nurse I saw them taking organs from a patient and I went through that experience. I was naïve, even though I was in my mid-20’s, I didn’t know the process and it gave me nightmares for months. The patient at the end of it because we were student nurses we had to do care of the deceased and I witnessed the putting of the cotton wool in the eye sockets because they took the eyes and the sternum was cut open and it cracked and I think the patient looked beyond death so therefore that instigated the nightmares I was having. So, I would never stop anybody from donating their organs but then I wouldn’t”

Kellie [Senior Sister]

The words highlighted in yellow are the selected codes used to develop the theoretical category of ‘Mutilation’. Kellie’s experiences influenced my analysis and prompted me to write a memo (Memo 4). The constant comparative method underpinning the analysis influenced reflections on a donor family who had supported previous teaching events. I recall how a donor family talked about the “*physicality*” of the organ retrieval operation.

Memo 4:

The personal story offered by Kellie influenced my reflection about an earlier experience I had at an organ donation study day in approximately 2010. I recall a donor family talking about their experience of organ donation to a large group of healthcare professionals. Both donor parents reported that thinking about the “physicality” of the organ donation operation was incredibly painful and caused emotional upset. The word “physicality” links to the concept of Mutilation, as, in this context, the donor family are referring to the upsetting thoughts of organs being removed following death. This, combined with Kellie’s account, suggests that the donation operation was somehow traumatic and I wonder whether this contributes to relatives declining donation.

As the analytical process evolved, selective coding was used to develop the theoretical category of Mutilation. Excerpt 17 below, taken from the interview with Virginia, strengthens the theoretical category of Mutilation through her belief that patients “*have suffered enough*” and “*going to put that person through more trauma*”. Specifically, Virginia was asked during interview to consider whether profound grief influences relative / carer decisions to donate organs or not.

Virginia was asked about her thoughts of relatives being asked to consider organ donation following death of their relative.

Excerpt 17:

“I think that sometimes families do think like why is this happening to me, understandably, why has it happened to me and I know I have heard family say like you don't deserve this to the patient and it's so unfair and you don't deserve this. The thought them that they going to give consent to go through more after they have died, I think that that's too much for some families, the thought that they're going to put that person through more trauma, through more pain, you know families still see that it's their relative, it's still their loved one isn't it, they don't see it like we do, you know like they see it like still putting that patient through more I think that that weighs quite heavily on their minds”.

Virginia [Staff Nurse]

Virginia discussed her fear that the dying patient was going to suffer further following death and “they’re [transplant team] going to put that person through more trauma”. Similarly, Carlos was asked to consider his thoughts about relatives being asked to consider organ donation and revealed his personal belief.

Excerpt 18:

*“This is part of the testing and retesting, giving information to see what has been heard, letting them know that there is a process round this. Some families don’t really hear and it takes time for them to absorb the news. Asking for organ donation at this point is too much. **It’s a kin to taking everything away from them**. Sometimes I’m a bit uncomfortable when it’s obvious you’re going to take them as a donor and the family need more time”.*

Carlos [Consultant]

Table 5.2 below illustrates all the selective codes taken from the interviews with Kellie, Virginia and Carlos, helping with the identification of ‘Mutilation’ as a theoretical category.

Table 5.2: Selective coding used to form theoretical category

Selective Coding	Theoretical Category
Putting cotton wool in eye sockets	Mutilation of the dead body
They took the eyes	
Sternum was cut open & it cracked	
Patient looked beyond death	
Physicality	
Go through more after they have died	
That’s too much	
Going to put that person through more trauma	
Through more pain	
It’s a kin to taking everything away from them	

Similar findings have been reported elsewhere, for example Wheeler *et al*, (1994), reported that cultural belief had a powerful influence on donation outcome. The findings from their study stated that a cultural belief in an afterlife, with the need for all body parts, represented a significant barrier to organ donation. Furthermore, Bresnahan *et al*, (2007), investigated whether spiritual belief affected organ donation consent rates. Their findings suggested that spiritual connection was a significant predictor of behavioural intention, confirming a relationship with a negative attitude towards organ donation and fear of body mutilation (Bresnahan *et al*, 2007). The literature on the impact that cultural and spiritual belief has on organ donation and associated fear of mutilation is scarce. The similarities between the studies by Wheeler *et al* (1994), Verble and Worth (1999), Sque *et al* (2007) and Bresnahan *et al* (2007) confirm that Mutilation is consistent with the findings from Chapter 5, highlighting that the fear of body mutilation, as experienced by critical care staff, has significant impact on the support for the donation process.

The findings indicate that a great deal of human behaviour is triggered by events which become threatening through association with painful experiences. Indeed, Kellie during her interview described a deceased patient as “*looking beyond death*” following the organ retrieval operation. Such experiences, which could remain suppressed by critical care staff, stimulate defensive behaviour such as avoidance of the donation process (Bandura, 1977). Likewise, Marsh (2015), whilst working as a surgeon, recounts his experience of a conversation with a colleague following the discovery of a ‘corpse’ in the operating theatre as he started work:

“it’s just an organ donor – a brain dead injury from the ITU. Rather, what’s left of him. That cyclist from two nights ago. He didn’t make it despite surgery. Probably a good thing. The transplant team did a snatch last night. Heart, lung, liver, and kidneys – they took the lot, all in good nick. They were delighted. They finished later than usual and the porters were changing shift so they haven’t got round to taking him away yet”

(Marsh, 2015: p 130).

This conversation highlights the way in which people use metaphors and modifying words to describe the organ donation process. Moreover, certain words depict a vulturistic intent of the transplant team with body parts appearing as dehumanised objects. Ultimately, the findings suggest that critical care staff perception of body mutilation is deep rooted and complex. It is acknowledged that this perception escapes routine educational initiatives and resultant behaviour is governed by social learning processes.

Mutilation was highlighted in work by Nizza *et al*, (2016) who explored the reason why people had not signed up to become organ donors. Their study affirms the discrepancy between attitude and behaviour, how fear can inhibit positive donation actions. Specifically, the study by Nizza *et al*, (2016) reveals how the ability to detach from ‘the body’ affects the acceptance of organ donation and trigger difficult thoughts. In a similar way, the historical use of the term ‘organ harvest’ may influence critical care staff perceptions of the organ donation process. The term ‘harvest’ means some sort of ‘sacrifice’, as detailed by Sque *et al*, (2007), at the expense of a human life. In a similar way, Shaw (2010) explored the perception of critical care and donation professionals when using the term ‘gift’ in organ donation discourse. The study identified several problems with the ‘gift’ rhetoric, namely the downplaying of the human organs as consumer products. High profile media coverage, including the use of organs from executed Chinese prisoners, depicts organ transplantation as a commodity and “*bitter harvest*” (Gutmann, 2012).

Zwart (2014) describes the dying organ donor as a “partial object” of desire to an organ recipient. In this context, disembodiment and the fear of mutilation contaminates nursing practice, Lacanian analysis compares organ transplantation to other bodily practices involving bodily parts procured from others, such as cannibalism (Zwart, 2014). This rather profound analogy between two concepts, but both involving body parts, highlights the distance between an ‘internal’ or ‘external’ bodily object. Zwart’s (2014) work signifies a symbolic link between critical care staff experiences and the fear of body mutilation. As discussed in the previous section, findings confirm that professional inexperience is positively connected to an increased fear of body mutilation.

Arguably, fear that the deceased body will be mutilated or ‘incomplete’ for the afterlife affects critical care practice. Another way of understanding critical care staff fear that the deceased body will be mutilated is through the work of Bryan Turner. In this section I will briefly outline Bryan Turners concept of *Sociology of the Body* (Turner, 1997). I will then explore the relationship of sociology of the body with the fear of mutilation.

Turner (1997) argues that the contemporary problem of societal perception of the human body is an inheritance of Judeo-Christian discourse, the broken body of Christ heightening a fear of human frailty. Moreover, Turner (1997) argues the peculiar theme of cannibalism in Christian faith in which “*through transubstantiation, the bread and the wine are converted into the body and blood of the living Christ*”, renders the human body as sacred (p 105). I argue, in this context, perception of the intact human body becomes a critical issue.

Interestingly, Turner suggests, in the context of human taste for food, offal is particularly potent as a sign of ‘living’ flesh. He argues that organs such as hearts, kidneys, tongues and brains actually represent ‘living’ flesh, the process of cooking coverts the ‘living’ flesh into dead cooked meats. I am not suggesting that critical care staff view the preparation of offal

and organ donation in the same context, rather than Turner's theory is useful to understand the complex relationship between the life and death of human organs.

Deborah Lupton develops the point further and has interesting reflections on gendered eating and cooking. Lupton (1996) claims in her narrative *Food, the Body and the Self* that the historical killing of animals for food is 'definitely men's work' and, for this reason, the concept of a 'woman butcher' is almost unthinkable (p 108). In the female dominated profession of nursing, Lupton (1996) certainly offers an intriguing viewpoint, but her argument is too primitive and simplistic. Alternatively, I suggest that regardless of gender, societal acceptability of organ donation is influenced by a continuum of internal moral discourse connected to personal views about the deceased human body. I concur with the writing by Cregan (2006) concerning the sociology of death who suggests:

"While people may have been concerned with their own end and still suffered from fear of a savage death brought on by scientific 'progress', when one looks to the way in which bodies are interred, the monuments to and representations of the dead, one finds memorials that concretise the loss of the living far more than they mark on the lives of the dead" (p 37).

In relation to the fear of mutilation, Kearsal's (1996) work *Dying Well* deliberates changing death fears, arguing that the worlds of the living and the dead has moved from a period preceding death to the period preceding it. Kearsal suggests that unanticipated and sudden deaths, as in the case of most organ donors, the "*cultural consolations of societies were based on envisionments of individuals post-mortem fates*" (p 342). In this context, I also agree with the work of Griffin (1983), the dying patient lacks autonomy therefore the nurse becomes the protector of humanity. I suggest that the ambiguous period between dying and death provokes a *fear* of uncertainty regarding post-mortem fate. Thus, Virginia was concerned that the patient would "*go through more after they have died*", arguably a post-mortem fate symbolic of a "*bad death*" (Kearsal, 1996).

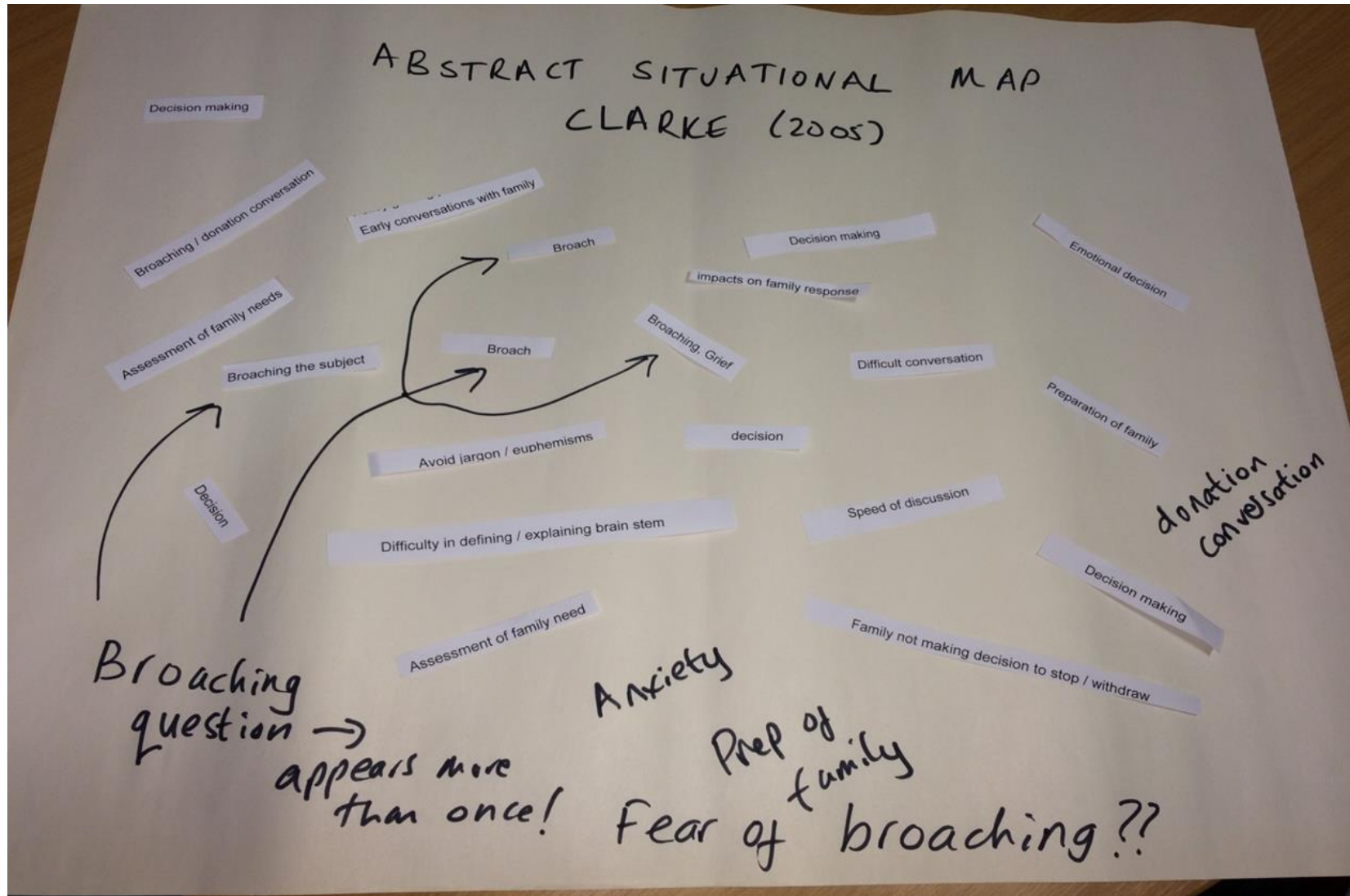
5.4 Theoretical Category 3: Broaching

The third theoretical category to emerge following data analysis is entitled 'Broaching' which relates to critical care staff anxiety with the donation discussion. As discussed in Chapter 2, Muthny *et al*, (2006) highlighted a critical need for psychosocial training in preparation for donation discussions. In a similar way, Salehi *et al*, (2013) reported high levels of stress amongst nurses caring for brain dead donors. Drawing on literature of moral distress in the donation discussion, St Ledger *et al*, (2013) explored moral dilemmas faced by critical care staff, concluding that unresolved moral distress is a potential barrier to organ donation.

The relationship between Fear of Broaching and successful donation outcome emerged as an important aspect to explore further. Following the first four interviews, I conducted a situational abstract map (Messy Map) as advised by Clarke (2005), this is observed below in Figure 5.4. Interestingly, not all literature provided a consistent perspective. A study by Brown *et al*, (2010) reported a positive correlation between families declining donation and failure to utilise expertise [SNOD] during donation discussions.

Given that theory is grounded in the data itself, studying and comparing data helps to illuminate the theoretical category of 'Broaching' (Charmaz, 2006). Six of the interview participants had reported anxiety with the donation discussion. Therefore, this concept was explored in greater detail through moving back and forward over the interview data. This process allowed the advancement of theory and, critically, the constant comparative method helped to detect relationships between abstract concepts and the theoretical category of Fear of Broaching. Memo 5 below includes initial reflective thoughts on the concept of 'Broaching' and critical care staff fear of donation discussions.

Figure 5.4: Abstract Situation Map 'Messy Mapping' (Clarke, 2005)



Memo 5:

I am starting to get a feeling that critical care staff have fear or anxiety with approaching families with an organ donation request. It is like there is a feeling of discomfort on behalf of the family. It is worth exploring whether critical care staff think that asking a family to consider organ donation will cause or add more stress. I want to explore whether staff think it is possible to deliver any worst news than their relative is dead or dying. I am not suggesting that critical care staff consider organ donation to be bad but the responses indicate that discussions regarding organ donation is causing upset and anxiety. Where do those anxiety drivers originate? This needs greater exploration.

The following excerpt, taken from the interview with Jenny who shares her first experience of organ donation, introduces the concept of Fear of Broaching. The words highlighted in yellow are the selective codes used to identify the theoretical category.

Excerpt 19:

“Ah ah, yes that was the first case I had when I first started so I was new to everything but really good, really supportive. I felt like they took control of it because I was worrying about me broaching the subject with the family but....”

Jenny [Staff Nurse]

The selective codes highlighted in yellow suggest that Jenny was anxious about the donation conversation. She reported feeling relieved that the specialist nurse had arrived and went on to describe her inexperience as a critical care nurse relating to the best time to broach the subject of organ donation with relatives / carers.

Excerpt 20:

“Obviously, confidence, I was newly qualified but still know it’s when to broach that subject, they’re upset, relatives poorly, dying and it’s just knowing when to broach that subject and who to broach it to”.

Jenny [Staff Nurse]

Table 5.3: Selective coding used in Excerpt 19 and 20 which supported the development ‘Broaching’ as a theoretical category.

Selective Coding	Theoretical Category
Worrying about me broaching the subject	Broaching
Who to broach it to	
When to broach that subject	
Broach that subject [organ donation]	

The data indicated that critical care staff did not relish the prospect of making an organ donation request to a grieving family. On the contrary, the respondents reported fear and anxiety with initiating organ donation discussions with acutely grieving relatives / carers.

The excerpts from Jenny highlight that a lack of experience may also impact on confidence with broaching the subject of organ donation with bereaved relatives. Martin and Carlos, who had previously mentioned that inexperienced staff struggle with the emotional demands of organ donation, alluded to anxiety with the donation request. Thomas was discussing the dynamic of a busy emergency department and was asked whether the organ donation request caused additional harm to the family.

Whilst Thomas does not directly express concern with an organ donation request, his response suggests that the organ donation request might upset some relatives / carers.

Excerpt 21:

*“It's still a challenging thing but it would be something that is the norm opposed to something that's not the norm. Would it harm the family? **It might upset some of them** but at the same time I do have some experience whereby I broached it down here in the A&E department on a particularly frenetic day”.*

Thomas [Consultant]

The highlighted segment above within Excerpt 21 suggests that location and workload may impact on donation discussions. In this context, Thomas [a doctor] talked about Broaching donation on the emergency department as opposed to the critical care unit [upstairs]. During his interview, Carlos, who was an experienced senior doctor, was asked whether an upset family could impede donation discussions.

Excerpt 22:

*“I'm sure it does, in the last situation that we had **I was very anxious** because some **family members were very hostile** because of the suddenness of what had happened to their mother, they didn't seem to be accepting and so the **discussions took a long time** and it was with ***** [name of resident SNOD] and a number of points we thought we might turn the discussion towards donation and the patient was on the register because of the **behaviour of the family** we were very anxious not to mention it too soon for **fear of getting a hostile response**”.*

Carlos [Consultant]

Table 5.4: Selective coding used in Excerpt 21 and 22 which supported the development of Fear of Broaching as a theoretical category.

Selective Coding	Theoretical Category
It might upset some of them	Broaching
Very anxious	
Family members were very hostile	
Discussions took a long time	
Behaviour of the family	
Very anxious not to mention it [organ donation] too soon	
Fear of getting a hostile response	

The response provided by Thomas and Carlos (excerpts 21 and 22) illustrate the challenges faced by clinicians regarding the organ donation request. It appears that gauging when is the most appropriate time to make a donation request generates anxiety. Virginia was asked what factors made the organ donation conversation challenging with families. Virginia was asked whether organ donation should always be considered and she shared her personal experiences (excerpt 23).

Excerpt 23:

“You know what the thought of speaking with a family and this is the pinnacle of our career at this stage of life, to have that conversation is hard, we are encouraged to leave it for the specialist nurse. You know we know they are the specialist and the ones that have got the training and have got the expertise. You know you don't want to be saying the wrong thing do you? You know you don't because that is completely going to make that family, that's it takes one to say that's going to, that's not the right thing to say that's going to. Once that initial conversation has been had you're going to be the one that's following it up, you know to keep that thought process alive for the family really and you know it's a minefield it really is, you know you've got to constantly assess their opinions and where they're at in that decision making process and that is really hard work you know of course it is”.

Virginia [Staff nurse]

The response from Virginia provides a slightly different perspective relating to anxiety with the donation discussion. Her account suggests that the conversation should be held by an appropriately trained and specialist individual, namely the SNOD. Virginia's interview prompted the following memo (Memo 6). Pink, who was an experienced critical care nurse, was asked whether her experience made the donation discussion any easier. Similar to Jenny, Carlos and Virginia, Pink reported anxiety with the donation discussion and explained it was challenging for all members of staff, regardless of years of experience.

Memo 6:

Virginia influenced my thinking and I recall a patient I was called to a few years ago. The patient had suffered a cerebral aneurysm and had surgical clippings to repair the aneurysm. She was 2 weeks post neuro surgery and recovering well. She had a tracheostomy tube in situ and was being transferred from the ICU bed to a chair. Unfortunately, the tracheostomy tubing became dislodged in the hoist. The most horrendous sequence of events unfolded but the patient suffered hypoxia and had a cardiac arrest. Despite resuscitation, the patient had irreversible brain damage and the decision was made to withdraw life sustaining treatment. I was called to speak with the family and offer the option of organ donation. On my arrival, the family were devastated and extremely angry, even hostile towards staff. However, a donation request was made and the family agreed. Despite their grief and anger with care staff, organ donation was still an option the family wanted to consider. I sympathise entirely with Virginia as I was nervous of broaching the subject of organ donation. Some cases just seem worse than others.

Pink was asked about whether her professional experience made the donation discussing discussion any easier.

Excerpt 24:

“I think that it's very difficult for the newly qualified staff nurses. But it's difficult for us too, even though I have 15 years of experience it's still an emotive issue. You know it's not easy even after 15 years, to talk to somebody about this [organ donation] but it's more difficult for new staff, you know they are young just come into nursing, they have not really experienced these emotions because. You know it's two sides, it's the families and the patient's emotion and the nurse's emotion”.

Pink [Sister]

Table 5.5: Selective coding used in Excerpt 23 and 24 from the interviews with Virginia and Pink.

Selective Coding	Theoretical Category
To have that conversation is hard	Broaching
You know you don't want to be saying the wrong thing do you?	
it's a minefield it really is	
it's very difficult	
it's still an emotive issue	
it's not easy even after 15 years, to talk to somebody about this [organ donation]	

Further studies have reported on the anxieties faced by critical care professionals regarding an organ donation request. Oróy *et al* (2013) discovered that judging when to make the organ donation request to distressed relatives caused significant worry amongst critical care staff. Undoubtedly, the organ donation request appears to cause anxiety amongst staff and I intend to explore the origin of this anxiety in more detail. These findings indicate that the anxiety pertaining to the organ donation request is a social construction to deal with a complex and difficult situation. Making the donation request, as discussed in Chapter 2, is known to be one of the most stressful and challenging tasks in nursing (Stoeckle, 1990; Stroud, 2002; Warnock *et al*, 2017; Bleakley, 2017). Additionally, my findings indicated that *Fear of Broaching* was mentioned in seventy-five percent of the interviews. The excerpts are

intriguing in that, regardless of years of experience, a tangible *fear* is detectable when making a request for organ donation.

Menzies-Lyth (1960) discusses the concept of *Social Systems as a Defence Against Anxiety* and I argue her work can be exploited to better understand anxiety in the context of making an organ donation request. Menzies-Lyth (1960) conducted research into the nature of anxiety amongst the workforce in a large London teaching hospital. In particular, she investigated the social systems employed by nursing professionals (student nurses and trained staff) as a defence against anxiety. During her study, Menzies-Lyth discovered that nursing professionals developed social systems to cope with everyday reality of the profession and emotional outbursts from patients. Relatives were dealt with in a brisk reassuring behaviour and advice of the “*stiff upper lip*” (Menzies Lyth, 1960: p 445). Interestingly, Menzies-Lyth (1960) reports that in an attempt to reduce anxiety within the nursing profession, the organisation became obsessed with employing “*responsible and competent*” people (Page 448). Similarly, I suggest, the UK-wide implementation of ‘resident’ SNOD’s has deskilled the bedside critical care nurse from coping with challenging conversations.

Perhaps the most salient aspect of the work by Menzies-Lyth (1960) was her observation on the *Deprivation of Personal Satisfaction*. In much the same way, anxiety, success and satisfaction were dissipated amongst the workforce. Critical care professionals only observe one aspect of organ donation, the dying donor, failing to see “*patients get better in a way they could easily connect with*” (Menzies-Lyth, 1960; p 457). Therefore, I argue that integration of donor stories and celebration of successful donation outcomes needs to be a feature within critical care teaching and training. However, I acknowledge it is challenging for critical care professionals to engage with the thought of a transplant recipient during times of organisational constraint, as discussed above (Warnock *et al*, 2017).

Menzies-Lyth argues that the focus of anxiety within the nursing profession is rooted in the relationship with the patient [relative]. She reported that the closer and more concentrated the relationship, the more the nurse was likely to experience the impact on anxiety. Griffin (1983), discussed in Chapter 1, suggests that the autonomy of a person is relinquished during critical illness, producing a situation whereby the patient cannot express personal needs or belief. The critical care nurse becomes a “*protector of humanity*” (Griffin, 1983; p 291) and the donation discussion would elicit a “more concentrated” relationship with the relative. In a similar way to the seminal writing by Menzies-Lyth (1960), findings from the interviews suggest that the donation discussion is likely to impact on increased anxiety, making an organ donation request is an unattractive prospect for some critical care professionals. This would certainly fit with the findings, which suggest that critical care staff fear broaching the subject of organ donation with relatives of dying patients.

My curiosity was roused by a number of authors who explored the ethics of conversation and negotiation within nursing care. Skott (2003) claims that in order

“to do what is right and good for someone requires that one has a reliable understanding of what is best for the person in moments of choice”

(p 368).

As argued by Griffin (1983), autonomy is relinquished during critical illness. In a similar way, I contend this bioethical principle is obsolete when it is divorced from the person it is supposedly meant to protect and benefit. Arguably, autonomy is the most important bioethical principle underpinning nursing care but people who are unconscious lack the ability to make decisions about their care (Baillie and Black, 2015; Neilen, 2013). Without specific guidance from the patient, I believe that critical care professionals fear broaching organ donation because they cannot involve the patient directly. Indeed, routine checking of

the organ donor register (ODR) may be helpful to ascertain previous known wishes but only thirty percent of the UK population are active on the ODR (NHSBT, 2017).

In her book *On Death and Dying*, Kübler-Ross (1969) explores societal attitudes toward death and dying, claiming society has an increasing anxiety in relation to death. Her theory argues that bereaved relatives enter a primary stage of 'anger' following delivery of bad news. This suggests that critical care professionals are expected to approach relatives for organ donation during the primary stage of anger. Importantly, Kübler-Ross (1969) contends that society that is "*bent on ignoring and avoiding death*" (p 10). In a similar way, critical care staff could be fearful of the impending death and fearful of a potential hostile response from an 'angry' relative / carer.

Kübler-Ross (1969) claims that modern medicine has moved from a humanitarian endeavor to a new "*depersonalized science*" (p 10) which centres on prolonging life rather than eliminating human suffering. In this context, Kübler-Ross's theory could regard care of the organ donor as a practice that is life prolonging rather than lifesaving. The work by Kübler-Ross (1969) is consistent with Glaser and Strauss's (1965) assertion that medical professionals are conditioned to save and prolong life at all costs.

During autumn 1965, Elisabeth Kübler-Ross embarked on a research project that intended to explore "*crisis in human life*" (p 18) through a series of interviews with terminally ill patients. She discovered that doctors became very defensive when it came to talking about death and dying of patients in their care. It appears that the hospital staff, including nurses, actively avoided Kübler-Ross as the researcher. She reports encountering stunned looks and some doctors "*protecting*" the patient from the research project saying patients were too sick, weak or tired. In a similar way, I suggest that the act of approaching relatives for organ donation necessitates the critical care professional to grapple with complex emotions. The

fear of broaching heightens uncomfortable feelings for some critical care staff and I agree with writing by Kübler-Ross (1969):

“Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending end, which is so frightening and discomfoting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being?”

(p 8).

This seminal work demonstrates that death is a complex subject and that hospital staff respond to the death and dying of patients in curious ways. The real issue is the critical care nurse / doctor having to confront reality that their patient is not going to survive critical illness. In an attempt to “*protect*” the patient in their care, it appears that a defensive response by some critical care staff is to *fear broaching* the subject of organ donation.

5.5 Theoretical Category 4: Experiential Competence

The final category to be identified following data analysis was entitled ‘Experiential Competence’. Each of the study participants made reference to the importance of professional experience related to the organ donation process. Specifically, ‘Experiential Competence’ encompasses not only experience of the organ donation process but the formulation of professional and therapeutic relationships with the relatives of dying patients. A Messy mapping exercise proved useful in developing the theoretical category further and is observed in Figure 5.5. I suggest that experiential competence is a critical factor in positive donation outcomes and that professional inexperience causes fear with all aspects of the donation process, including the testing for brain stem death. Jenny, who was a newly qualified staff nurse, was asked about her experience of referring a patient to the on call Specialist Nurse – Organ Donation.

Excerpt 25:

“Ah, yes that was the first case I had when I first started so I was new to everything but it was really good, really supportive. I felt like they took control of it because I was worrying about me broaching the subject with the family and I didn't have any experience so was a bit worried”.

Jenny [Staff Nurse]

Jenny reported that her professional inexperience caused a degree of anxiety with the organ donation process. Equally, the following excerpt from the interview with Martin indicated that Experiential Competence was an important consideration when caring for dying patients. Martin, who works as a senior charge nurse, was asked about how he prepares to deliver bad news to relatives.

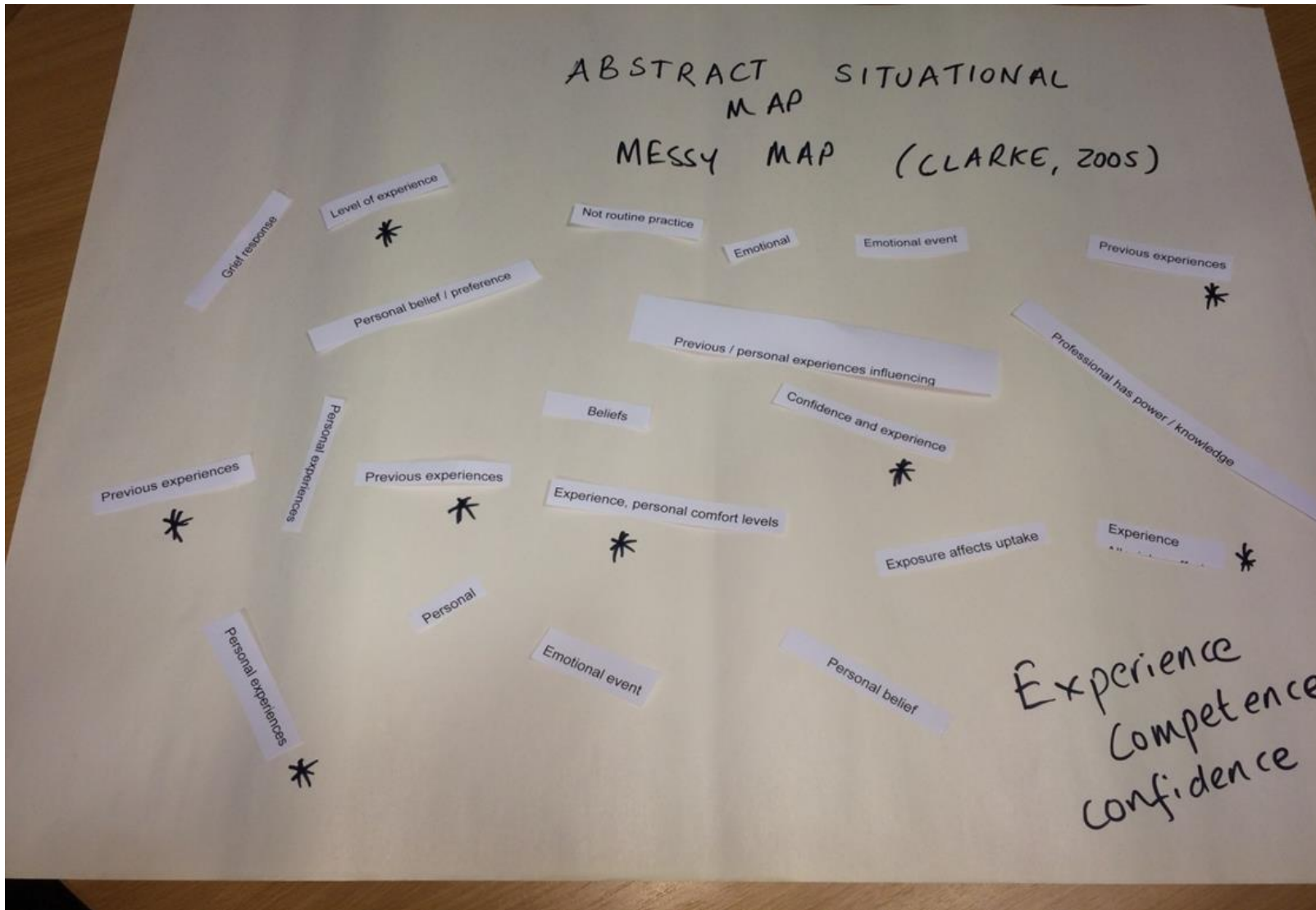
Excerpt 26:

“We've got this policy and guidelines in place were the consultant and registrar has to make contact with the family within 24 hours. So it starts then with the medical team. With the nursing team, the bedside nurse starts to get to know the family, straight away we try and introduce, we try and work with continuity of care, so the same nurse will go back to the patient and as you see the patient is deteriorating we always try as a nursing team to put the right nurse with the right patient who have got experience. Some nurses are better than others at dealing with things like this”.

Martin [Senior Charge Nurse]

Martin's comments suggest that some nurses are better at dealing with dying patients and the organ donation process than others. He also mentions the importance of experience when deciding which nurse to place at the bedside of dying patients. These findings suggest that professional inexperience generates *fear* and this influences interaction and conversation with relatives of dying patients. Martin's interview influenced the following memo (Memo 7).

Figure 5.5: Abstract Situation Map 'Messy Mapping' (Clarke, 2005)



Memo 7:

Martin believes there is significant merit to the same nurse returning to the same patient if providing end of life care. He mentioned the formation of a professional relationship with the family and that some nurses are better at doing this than others. Martin has a great deal of professional experience and he was convinced this makes things easier when a patient is at the end of life. He explained that consistent care builds trust with the family. This suggests that establishing a therapeutic relationship is an important issue for the critical care nurse. It is worth exploring whether these elements influence decisions to donate. He suggested that personal beliefs regarding organ donation could contaminate the relationship with the relative / carer. Significantly, Martin shared his own personal health struggles and that his long term condition influenced his belief that organ donation would provide "a better quality of life" for someone.

Martin has discussed some important and intriguing issues. I am particularly interested in the idea that a strategic placement of the most experienced nurse at the bedside could positively affect donation outcomes.

Following the responses from the first three interviews with Jenny, Martin and Thomas, Carlos was asked whether he thought that placing an experienced nurse at the bedside of a potential organ donor would influence outcome.

Excerpt 27:

*"Oh yes, I mean I've not thought about whether it happens or not. I've not sort of registered that but thinking about it in a theoretical context then it would make sense. It might not make sense there and then because while they're being admitted, usually there's a level of active treatment somebody who may be eligible for brain stem death testing, then **having a more experienced nurse at the bedside is going to be more comfortable with that situation**".*

Carlos [Consultant]

Carlos suggested that having a less experienced nurse during the admission phase might prove unhelpful during preparation for potential donation activity the following day.

Although the formal breaking bad news conversation and brain stem death testing may occur 24-36 hours following admission, Carlos maintained that an experienced and competent nurse from the outset would instill confidence with the family. Finally, Carlos believed that the “*experienced nurse*” would be more comfortable with the overall situation. Additionally, during their interviews, Pink and Betty were asked whether their experience made exposure to the organ donation process any easier.

There is some evidence to suggest that professional inexperience leads to higher levels of anxiety and this is exemplified in the writing by Michael Eraut. Eraut (2007) conducted a longitudinal study following newly qualified staff nurses’ first three years of service.

Specifically, Eraut (2007) focused on early career learning relating to the development of professional understanding and tacit knowledge. Eraut (2007) argues that “*working alongside others*” allows the inexperienced to “*observe and listen to others at work*” (p 409). In a similar way, I would argue that placing inexperienced members of the critical care team with experienced colleagues, in the context of caring for dying patients, is a mode of learning that can enhance “*professional identity*” (p 409).

Interestingly, Eraut (2007) describes how newly qualified nurses deal with challenging tasks and roles. He asserts that on-the job learning, if well supported and successful, leads to improved levels of confidence and motivation. Therefore, I suggest that allocating an inexperienced member of staff to care for a potential organ donor is unwise and harmful to successful donation outcomes. Finally, Eraut (2007) discusses the importance of early career professionals “*locating resource people*”, suggesting that professional learning is enriched by developing networks with “*knowledge resource people*” (p 415). In order to reduce anxiety and fear associated with the donation process, it appears logical for inexperienced staff

members to establish strong links with the embedded Specialist Nurse – Organ Donation and work collaboratively with experienced colleagues.

Excerpt 28:

“I think that it's very difficult for the newly qualified staff nurses. But it's difficult for us too, even though I have 15 years of experience, it's still an emotive issue. You know it's not easy even after 15 years, to talk to somebody about this but it's more difficult for new staff, you know they are young just come into nursing, they have not really experienced these emotions because. You know its two sides, it's the families and the patient's emotion and the nurse's emotion”.

Pink [Sister]

The constant comparative analysis identified links with the quotes provided by Carlos and Pink. This prompted me to ask Betty what skills she believed are involved in the care of a potential organ donor.

Excerpt 29:

“I don't know if it's a set of skills that can be learnt, I think it's something that comes with experience, erm so recognising that the treatment we are giving is potentially futile, I think that's a big factor and I think it comes with experience. Over the years of my experience I think I find it easier now to say that this patient isn't going to survive, opposed to when I first started”.

Betty [Sister]

There is a link with the intuitive-humanistic model described by (Benner, 1982) which offers insight in to how professional experience impacts upon critical care staff perception of organ donation. Jenny, a nurse for 18 months, reports “being thrown in at the deep end” as her career commenced on the critical care unit. She mentioned her discomfort with relatives witnessing brain stem death testing saying “no, I wouldn't agree with that, it's quite invasive”. In this context, Jenny is a ‘Novice’ practitioner who has little or no experience, needing objective measures to work in. Conversely, Thomas, who had been a doctor for 21

years, was asked about relatives witnessing brain stem death testing and responded “I don't have an issue with it. I'm quite extreme in that I'm quite happy to have people in”. This displays a level of professional maturity, an ‘Expert’ practitioner who no longer relies on analytical principles and can grasp situations intuitively (Benner, 1982). This is consistent with the findings and I suggest that participants regard experiential competence as a motivating and influencing factor when engaging with organ donation. Table 5.6 shows how selective coding was used to identify ‘Experiential Competence’ as a theoretical category.

Table 5.6: Selective coding process – ‘Experiential Competence’

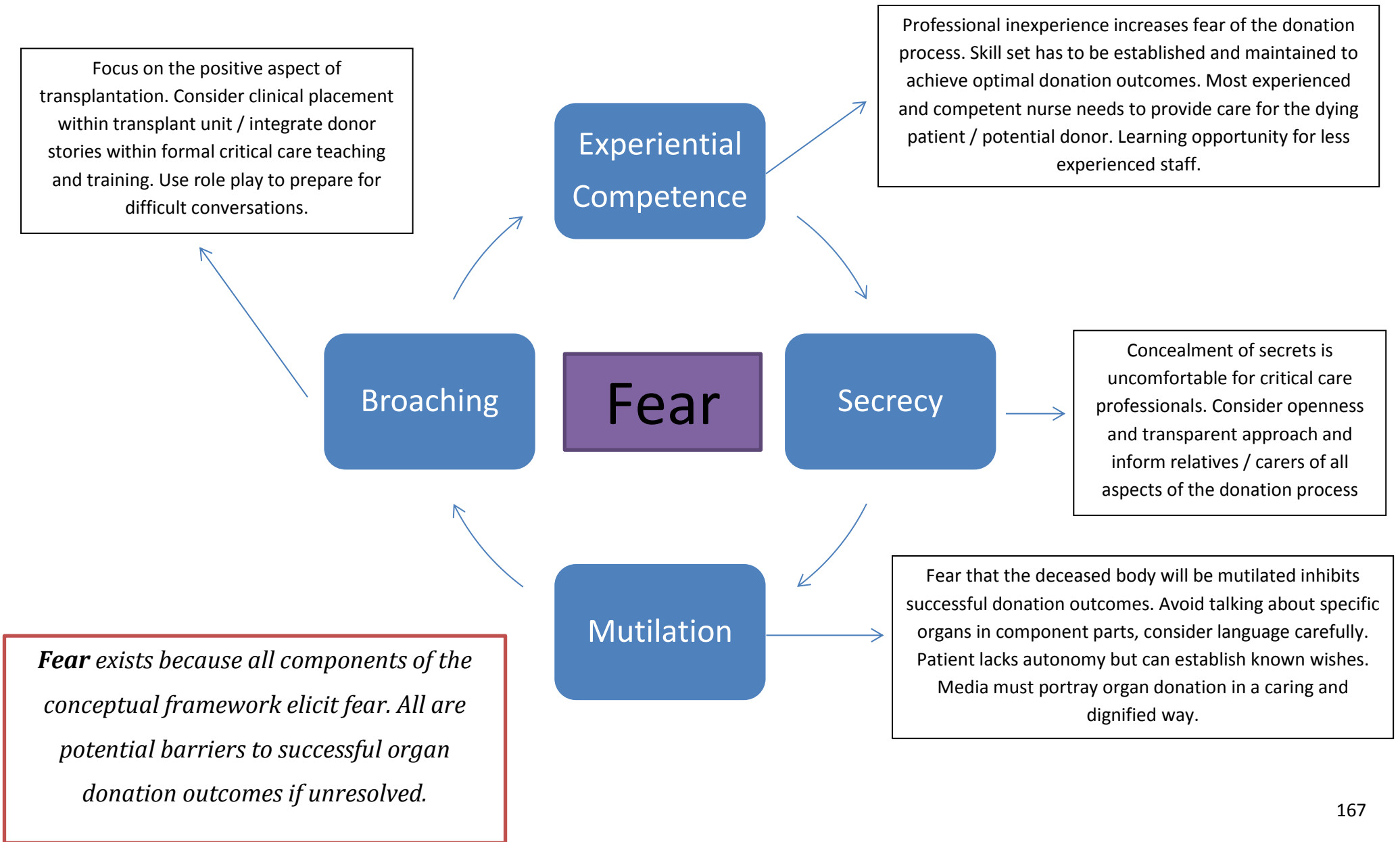
Selective Coding	Theoretical Category
new to everything	Experiential Competence
I didn't have any experience so was a bit worried	
put the right nurse with the right patient who have got experience	
Some nurses are better than others at dealing with things like this	
having a more experienced nurse at the bedside is going to be more comfortable with that situation	
very difficult for the newly qualified staff nurses	
15 years of experience, it's still an emotive issue	
it comes with experience	

Within chapter 2, Camut *et al*, (2016); Lin *et al*, (2014); Salehi *et al*, (2013); Meyer *et al*, (2012); DoH, (2008); Muthny *et al*, (2006); Jacoby *et al*, (2005) had identified education and training as critical elements affecting donation. Meyer *et al*, (2012) explored ICU staff competence in the donation process, concluding that an educated workforce [critical care staff] was pivotal to successful donation outcomes. The findings from this study are broadly consistent with the study by Meyer *et al*, (2012) in that professional inexperience affects confidence when engaging with the donation process. However, I surmise that placing the most experienced and competent nurse at the bedside of dying patients could positively influence donation outcomes. Equally, Warnock *et al*, (2017) discuss, in the context of breaking bad news, that inexperienced staff may feel they do not have enough skill or knowledge to competently perform their duties. The findings suggest that experiential competence has significant impact on the donation process and outcome.

In summary, four theoretical categories emerged from the analytical process including: ‘Secrecy’, ‘Mutilation’, ‘Broaching’ and ‘Experiential Competence’. The four categories lead to the development of a conceptual framework centred on a core category entitled ‘Fear’ (Figure 5.6). The development of the conceptual framework was not merely a collection of theoretical categories but a construct whereby each concept plays an integral and interlocking role (Jabareen, 2009).

Moreover, the conceptual framework does not present hard facts, rather my interpretation following data analysis. The use of grounded theory methodology ensured I used a robust analytical framework to guide my interpretation of the data and final analysis. The conceptual framework for positive donation outcome functions on a cyclical pattern composed of the four theoretical categories of ‘Secrecy’, ‘Mutilation’, ‘Broaching’ and ‘Experiential Competence’.

Figure 5.6: Conceptual framework for positive donation outcome



5.6 The Core Category: Fear

Constructivism assumes that there are multiple social realities operating concurrently rather than one specific “*real reality*” (Charmaz, 2006). In a similar way, findings indicate that the construction of *Fear* as a core category derives from the amalgamation of the four theoretical categories. The interplay of the four theoretical categories was central to the formation of the core category, leading to the development of a conceptual framework (Figure 14).

Consistent with my epistemological assumptions concerning the social construction of reality, fear can be explored from a sociological perspective. Tudor (2003) suggests that fear has been traditionally explored psychologically, as one of the emotions. Tudor (2003) argues that fear can be examined macroscopically, arguing for the “*existence of a distinctive culture of fear*” (p 238). In his writing, *A (macro) Sociology of Fear*, Tudor (2003) discusses how ‘fearfulness’ manifests as a normal way of life in modern society. Barbalet (1998) encapsulates how the social environment [critical care] elicits fear:

“The object of fear [organ donation] is not adequately conceptualised as a threatening agent who or which should be avoided. Rather the object of fear is an expectation of negative outcome”

(p 240).

Interestingly, Tudor (2003) suggests that if fear is experienced and articulated over a prolonged period of time, it is likely to be open to socially constructed patterns of “*reinforcement and ritualisation*” (p 241). Therefore, it appears logical to assume that if critical care staff anticipate *fear* at approaching relatives for organ donation, a ‘culture of fear’ is likely to prevent positive donation outcomes.

The findings revealed that the participants experienced fear frequently, and they described their subsequent anxiety relating to all aspects of the organ donation process. In a ‘Secrecy’ context, *Fear* relates to the concealment of secrets because critical care doctors and nurses

are fearful that the family might overhear a referral of their relative to the on call specialist nurse – organ donation. The second theoretical category entitled ‘Mutilation’ is concerned with *fear* that the post-mortem body will be harmed or mutilated in some way following death. Thirdly, *Fear*, in ‘Broaching’ context, derives from fear that an organ donation request will add pain and anguish to grieving relatives / carers. Finally, *Fear* in an ‘Experiential Competence’ context refers to doctors and nurses fear that professional inexperience could cause harm to relatives of dying patients and disrupt the complex donation process.

Deliberation on whether the psychological basis for fear is innate or acquired is enduring. Early theorists including Valentine (1930), assert that fear has an innate physiological basis. However, other scholars argue that fear is an acquired learned response (Gray, 1987). The findings from the study are broadly consistent with the writing by Gray (1987) who presented five principles which need to be considered when exploring the origins of fear including: Intensity, Novelty, Special evolutionary dangers, Stimuli arising from social interaction and Conditioned fear stimulus. Gray’s theory of fear stimulus can be modified to explore the emergent core category. Figure 5.7 is an adaptation of Gray’s theory of fear stimulus and offers a new perspective on how fear manifests during the organ donation process.

Figure 5.7: Adaptation of Gray's Theory of Fear Stimulus

(1) Intensity: As highlighted in Chapter 2, organ donation and caring for dying patients is a recognised emotionally draining nursing duty

(2) Novelty: Chapter 1 identified deceased organ donation as a relatively rare phenomenon

(3) Special evolutionary dangers: Fear that develops over time including negative organ donation media coverage and negative association with demands of caring for acutely grieving relatives / carers

(4) Stimulus arising during social interaction: Critical care staff are forced to work with 'strangers' [specialist nurse – organ donation] and discuss sensitive donation issues with 'strangers' [relatives / carers]

(5) Conditioned fear stimuli: Fear arises from exposure of stage 1 – 4, rendering some critical care staff fearful of the organ donation process

Gray's theory suggests that one stimulus of fear derives from social interaction and this can be explored using the seminal writing of Jewson (1976). *The Disappearance of the Sick-man from Medical Cosmology*, as identified by Jewson (1976), could still be applied in the context of clinicians experiencing fear at approaching relatives for organ donation. Intensive care nurses and doctors are concerned with diagnosis and pathology which, in turn, appears to have eclipsed the patient's own interest in preventing the unnecessary prolongation of life and suffering due to critical illness. Jewson (1976) asserts that 'modern' medicine is based less on the satisfaction of the patient but more upon recognition among professional peers.

This has resulted in *social distance* between the sick and medical investigators [sic], creating a palpable detachment from the demands of the sick (Jewson, 1976). It could be argued, applying the philosophy of Jewson (1976), that organ transplantation is a life ‘prolonging’ endeavour but some critical care practitioners, justifiably, may view the organ donation process as prolongation of unnecessary human suffering. The patient’s organ is failing and medical knowledge has allowed transplantation to become a viable treatment option but this does not necessarily fit with the emotional and spiritual belief of the patient (sick-man) or critical care staff as “*protector of humanity*” of the potential organ donor (Griffin, 1983: p 291). The impact of the medical model has great “*power*” over critical care staff and the sick-man [sic], making true ethical narrative and caring conversations challenging (Foucault, 1982; Gadow, 1996; Hess, 2003; Fredriksson and Eriksson 2003). From Jewson’s (1976) perspective the “*social distance*” between critical care staff and the relative / carer needs further exploration as it is unknown if this affects donation decisions and outcomes.

Therefore, I suggest that the fear of being judged by other health professionals could cause some critical care professionals to view organ donation as a personal failure to save life.

Essentially, medical innovation has shifted away from a network of primary relationships with the sick toward a network of secondary relationships with other medical professionals.

Furedi (2007) supports the theory offered by Tudor (2003) stating that fear is socially constructed and the impact of fear is determined by the situation that people finds themselves in. Essentially, Furedi (2007) argues that fear is a product of ‘self’ and the interaction of ‘self’ with others. Rather than focusing on the biopsychological origins of fear, Furedi (2007) explores the meaning attached to fear and the “*rules and customs that govern the way in which fear is experienced and expressed*” (p 2). For example, organ donation poses no direct threat to life or security of the critical care professional so it is intriguing why fearfulness is

present. Furedi (2007) suggest that “*feeling rules*” guide and influence behaviour on what we should fear and how we display fear (p 23).

The Alder Hey and Bristol Royal Infirmary organ scandals involved the unauthorised removal, storage and use of human tissue without lawful consent between 1988 – 1995 (DoH, 2001). During this period, organs were retained in more than 2000 pots from approximately 850 infants. This practice was uncovered following two public inquiries which led to the formation of the Human Tissue Act (2004). Both scandals caused public outrage and, at that time, support for organ donation diminished with people removing themselves from the organ donation register (ODR). This example illustrates how the meaning and experience of fear are shaped by cultural and historical factors. Furedi (2007) states that society associates fear with a clearly formulated threat: For example, fear that organs will be taken without lawful consent or fear the body will be mutilated following death.

Furedi (2007) and Tudor (2003) both argue that fear is a powerful force that dominates individual behaviour. Both scholars suggest that fear becomes volatile when it is not focused on any specific threat. Findings from the study suggest that fear is experienced by critical care staff at each stage of the donation process. This creates a ‘culture of fear’ for some staff and anticipation of the worst possible outcome is perpetual (Furedi, 2007). For example, fear that the family might overhear a referral to the on call Specialist Nurse – Organ Donation or fear of causing harm to the patient / relative due to professional inexperience.

5.7 Chapter Summary

This chapter explored the findings of the study following data analysis. Four theoretical categories emerged entitled 'Secrecy', 'Mutilation', 'Broaching' and 'Experiential Competence'. Each theoretical category was discussed using contemporary literature and evidence. A core category entitled 'Fear' was created which supported the development of a conceptual framework. To recapitulate, this chapter explored the concept of critical care staff fear at almost every aspect of the donation process. A key area of focus was *Fear* and I do not intend this title to be provocative, rather to be descriptive of the fear as experienced by critical care staff. I have argued that the *Fear of Mutilation* encapsulates two themes, fear the deceased body will be harmed and fear of inflicting serious harm on relatives / carers during the donation process. Finally, the findings suggest that the substantive theory offers a new and original method of removing some of the existing barriers to the organ donation. The final chapter provides a personal critical reflection, recommendations for practice, limitations of the research and concluding thoughts.

Chapter 6: Personal Reflection, Recommendations for Practice, Study Limitations and Conclusion

6.1 Introduction

Constructivist grounded theory research suggests that reflexivity is an important component of the research process (Corbin and Strauss, 2008; Charmaz, 2014). Therefore, I have elected to start this chapter with a personal critical reflection of the professional doctorate journey over the last six years (Lee, 2009). Critical reflection is an important part of the research process as it facilitates personal learning and development during the doctoral journey (Oliver, 2014; Lee, 2009). Next the chapter identifies the relationship between the study findings and recommendations for practice, including suggestions for future research. The limitations of the study are discussed with a specific focus on the quality, credibility, originality and resonance of the research (Charmaz, 2006). Finally, the thesis presents concluding thoughts of the researcher and considers the implications of the thesis on personal and professional practice.

6.2 Personal Critical Reflection

Dewey (1933) refers to reflection as “*assessing the grounds of one’s beliefs*” (page 9). Dewey’s definition of reflection echoes as I consider my experience of the doctoral level study over the last six years. I have reflected extensively on how the professional doctorate and my research has influenced personal attitude towards organ donation. When I started the professional doctorate in 2012, I was a specialist practitioner and somewhat entrenched in my beliefs from the clinical role. However, in March 2016 I was successfully appointed as a Lecturer in Nursing and the move to academia allowed me to remove the subjective lens of

my fixed “*clinical gaze*” (Jewson, 1976). I argue that this was a critical point in my doctoral journey, as my writing and thinking at that time, focused too heavily on clinical issues and statistics. The taught element of the professional doctorate equipped me with the skills to better understand the literature and research surrounding my specialised subject.

Moreover, the taught element of the doctorate equipped me with theoretical skills, but the journey of collecting data and change in employment circumstances facilitated greater analytical reflection on my research. The early part of my doctoral studies focused on theoretical perspectives of my profession, an important element prior to starting the study. This encouraged me to ask “who I am”, essentially situate myself in the research and better understand the origins of my epistemological views and ontological assumption.

In Chapter 1, I discussed my first experience of organ donation from a patient called Jayne (pseudonym). At this point in the journey, it was my belief that making a request for organ donation would add further stress and anxiety to Jayne’s grieving family. However, I also noted that I was personally *fearful* of causing harm to a patient and relatives in my care. Hence, this thesis has explored the experiences of critical care staff regarding organ donation following the death of a patient.

The findings have confirmed that *fear* doesn’t go away and is a shared phenomenon amongst critical care staff. Therefore, the thesis contends that the research extends our understanding of how *fear* influences professional practice and organ donation outcome. I reflexively noted that my own feelings, engendered by a number of personal and professional experiences, had influenced my own practice. Additionally, I remained perplexed as to why the family refusal rate for organ donation had remained fixed at 40% over the last decade (NHSBT, 2017). The thesis argues that the findings from the study contributes to our understanding of the way in which *fear* influences nursing practice at each stage of the donation process. I was aware

from anecdotal evidence that critical care professionals appear to avoid difficult donation discussions with relatives of dying patients. This caused great personal and professional frustration, as exploring critical care staff experiences of organ donation was taboo and a neglected area of research. The thesis revealed that profound issues surrounding the concealment of secrets, fear of mutilation, fear of broaching and professional inexperience appeared to influence decision making in relation to organ donation.

The professional doctorate journey has been a significant part of my life for a number of years. There has been occasion when the academic rigour attached to doctoral level study proved personally, professionally and intellectually demanding. However, I am confident that I arrive at the end of this journey as a completely different practitioner-researcher. After many years working as a specialist nurse – organ donation, the thesis has resolved many of the professional concerns and questions I had relating to organ donation. The doctoral process has encouraged me to think critically about clinical problems in a completely different way. In conclusion, I now understand why critical care professionals might *fear* the organ donation process for patients in their care. I accept that deep rooted personal belief, emotion and opinion are affecting the clinical practice of some critical care professionals. However, the findings from this study are a further step towards cultivating a positive donation environment that will surely result in more lives being saved through increased availability of donated organs. Findings from the thesis represent a new insight into the *fears* of critical care staff that perhaps challenges current practice and protocol.

6.3 Recommendations for Practice

In this section I discuss the recommendations for practice arising from the findings in Chapter 5. Additionally, I focus on the theoretical value of the findings and implications for practice. Chapter 5 identified four theoretical categories entitled ‘Secrecy’, ‘Mutilation’, ‘Broaching’ and ‘Experiential Competence’. The data analysis process revealed *fear* as the core category and this thesis proposes that *fear*, as experienced by critical care professionals, influences the donation outcome. As outlined in Chapter 5, the study has provided new substantive theory and suggested new ways of removing some of the existing professional barriers to successful donation outcomes. However, it is prudent to revisit the aims and objectives of the research in view of the study findings. The main aim of this study was supported by three associated objectives as identified below:

Research aim: A grounded theory study exploring critical care staff experiences of approaching relatives for organ donation

Associated objectives:

- To develop an understanding of the key factors that critical care staff feel influence relative / carer decisions to donate organs for use in transplant operations
- To determine whether critical care staff’s own experiences / perceptions / belief have influenced their conversations with the relatives / carers of dying patients and potential organ donors
- To develop new knowledge and theory about how critical care staff can best support the relative / carer decision regarding organ donation when caring for a potential organ donor

This thesis has concluded that there is a connection between *fear*, as experienced by critical care staff, and decisions affecting the organ donation outcome. The contribution of this study to nursing knowledge can be applied in a practical, educational and research context. I suggest that these findings, though only transferable within the critical care unit, contribute to a larger theoretical debate regarding critical care staff is discourse regarding organ donation. The narrative review of literature outlined in Chapter 2 identified 26 studies relating to the experiences of critical care staff and organ donation. Additionally, the narrative review of the literature confirmed that experiences of critical care staff regarding organ donation following the death of a patient is a poorly understood phenomenon. Therefore, this thesis offers an original contribution to established theory and recommendations for practice are identified below.

The thesis findings suggest that placing the most experienced member of staff at the bedside of dying patients reduces associated *fear*, stress and anxiety. This is not to exclude less experience staff from the care of dying patients but the thesis argues that professional inexperience generates *fear* of the donation process. However, this can only ever be enacted with adequate staff resources and appropriate skill mix. Conversely, the cost of treating a patient with end stage renal failure and associated renal dialysis far outstrips the cost of a kidney transplant (DoH, 2008). Therefore, there is an economic argument to support this recommendation for practice.

The findings revealed that critical care professionals dislike concealment of secrets from patients / relatives in their care. Furthermore, the findings suggest that adopting a transparent approach during the donation process reduces *fear* of secrecy. Bok (1989) discusses the tensions between concealing and revealing secrets. For example, critical care professionals experience anxiety when referring the dying patient to the on call specialist nurse – organ donation without knowledge of the relative / carer. This thesis revealed that critical care

doctors and nurses are suspicious of the secretive nature of the referral process for organ donation. Suspicion can be reduced by critical care nurses being open and honest during all aspects of the donation process. Moreover, the attendance of the on call SNOD to the referring critical care unit needs to be transparent and communicated to the relative. This can be achieved by the specialist nurse - organ donation being introduced to relatives / carers at the earliest opportunity.

Some of the study participants believed that certain words used to describe the donation process are distasteful and dehumanised the patient. For example, historically the organ retrieval operation was known as the “organ harvest”. The findings detected discomfort amongst critical care staff when mentioning specific body parts. Moreover, the findings confirmed that a concept of ‘list shock’ exists and I suggested that talking about specific body organs heightens a *fear* of disembodiment and mutilation. I argue that the listing of specific organs to gain consent is distressing for some relatives. As an alternative, ‘clustering’ the names of specific organs, such as ‘abdominal organs’, could be more acceptable for some. Further recommendation for practice from the findings is that critical care professionals need to give forethought to words used during the donation process. This includes ‘purging out’ negative words used to describe the donation process. This can be implemented during regular teaching, training and updates facilitated by the embedded SNOD.

Lack of confidence or belief that confirmation of brainstem death equates to whole body death leads to some critical care professionals *fearing* the donation process (Bleakley, 2017; Bell *et al*, 2004; Young and Matta, 2000). In Chapter 1 (Section 1.6) I highlighted the inherent tensions that staff experience regarding confirmation of brainstem death, even before the moral distress of organ donation is realised. The findings in the thesis suggest that some critical care professionals have a perception that the deceased body can experience pain following death. A recommendation for practice includes critical care staff observing formal

brain stem death testing, with support from the embedded SNOD. This could be achieved by critical care professionals engaging in mandatory rotation to a regional neurosurgical critical care unit where brainstem death testing is routine.

Current discourse in medical education (Foundation Years 1 and 2) advocates clinical rotation so that the practitioner gains relevant skills, knowledge and experience (Mandan *et al*, 2016). In a similar way, a study by Goldberg *et al*, (2011) explored the effects of a 1 week clinical rotation in palliative medicine on medical students. The study concluded that a brief clinical exposure in palliative care enhanced skills and knowledge in pain management. Those medical students that did not experience the clinical rotation and received only didactic training reported lower levels of knowledge and understanding.

Another recommendation for practice derived from the thesis findings includes regular debrief sessions for all critical care professionals involved in the organ donation process. Current UK practice is confined to ‘ad-hoc’ support from the specialist nurse – organ donation for staff involved in the care of an organ donor. This recommendation provides an opportunity to educate staff and support the development of resilience following emotionally draining events. If mandatory, I think this would strengthen robust working practices for future experiences of the organ donation process. Cameron and Brownie (2010) explored strategies to enhance resilience amongst registered aged care nurses. Their research concluded that:

“Emotional support from colleagues and mentors is an important factor in developing resilience in the workplace and in retaining staff. The nurses in our study valued the importance of debriefing and seeking validation from colleagues particularly when it was used as a learning experience to improve the management of clinical situations”

(Cameron and Brownie, 2010; p 69).

Wellington *et al*, (2012) argue that a professional doctorate normally concludes with recommendations that are applicable to practice as opposed to traditional theoretical recommendations. Throughout the thesis I have consistently reflected on the practical application of my research.

6.4 Recommendations for Further Research

The study findings highlighted two important areas where further research is indicated. The findings suggest that concealment of secrets causes anxiety amongst critical care staff caring for potential organ donors. Further research is needed to explore whether this has any significant impact on relatives' experiences, stress levels or donation outcome. Informing relatives / carers that a referral [of the dying patient] is being made to the on call specialist nurse – organ donation is currently unusual practice and it is unknown whether truth telling, in this context, has any impact on decision making and outcome.

The thesis findings, along with work by Verble and Worth (1999), suggest that traditional educational strategies are ineffective in removing the *fear* of bodily mutilation. Further research is needed on the effects of using alternative teaching strategies. This includes investigating whether education models used to treat phobias in cognitive behaviour therapy (CBT) can be adapted to meet the needs of staff who *fear* the deceased body will be mutilated during the donation process.

Over the last decade, use of high-fidelity simulated learning has become an accepted part of nurse education (Gates *et al*, 2012). Following their research into use of simulated learning with undergraduate nursing students, Gates *et al*, (2012), concluded that students who participated in high-fidelity simulation scored higher on clinical examinations than students

who did not. Furthermore, the study by Gates *et al*, (2012) provides evidence that simulated learning enhances knowledge acquisition. In a similar way, I suggest that use of simulated learning with integration of CBT techniques is a unique method of removing the *fear* of body mutilation, as experienced by critical care professionals.

6.5 Dissemination of the Research

Dissemination of the study findings and sharing of the new substantive theory is an important aspect of the research process (Oliver, 2014; Wellington *et al*, 2012; Charmaz and Bryant, 2007). Therefore it is important to consider where and how the findings will be disseminated.

I have deliberated the correct forum for dissemination so that the research has greatest impact. Therefore I plan to disseminate the findings within two separate professional groups.

Firstly, it is my intention to submit an abstract for oral presentation at the annual National Organ Donation Symposium. This event is attended by Specialist Nurses – Organ Donation (SNOD), Clinical Leads for Organ Donation (CLOD) and critical care professionals with an interest in organ donation. Secondly, I plan to submit an abstract for oral presentation at the annual British Association of Critical Care Nurses (BACCN) conference. This event is attended by critical care nurses from all over the UK and beyond. Oliver (2014) writes “*recommendations are normally directed to those individuals or organisations who are in a position to consider and implement them*” (p 185). I agree with Oliver and suggest that these two events will capture professionals who can support further dissemination of my research.

Working collaboratively with my supervision team, I plan to prepare a number of scholarly articles for publication in academic peer review journals thus ensuring that my research is widely disseminated. During the professional doctorate, I wrote an article which was

published in a high profile peer review journal relating to early emergent themes and challenges of brainstem death testing (Bleakley, 2017). Additionally, I was awarded the status of Research Scholar of the Florence Nightingale Foundation during December 2016 (Appendix 12). The scholarship required formal commissioned update reports on the research, two of which have been published.

6.6 Limitations of the Research

In this part of the chapter I will offer a critique of my research and suggest ways that my research could be improved. In order to achieve this, I will use the structured *Criteria for Grounded Theory Studies* as advised by Charmaz (2006). I will explore the credibility, originality, resonance and usefulness of my research. In addition, the discussion is enhanced by integration of criteria established by Lincoln and Guba (1989). Lincoln and Guba (1989) developed four criterion to assess the ‘trustworthiness’ of qualitative research studies [naturalistic inquiry] including credibility, transferability, dependability and confirmability.

6.6.1 Credibility

In order to determine credibility of the study, Charmaz (2006) asks whether the research “*achieved intimate familiarity with the setting or topic?*” (p 182). The framework by Charmaz (2006) encouraged me to inspect the original aims of the study outlined at the start of this chapter. The aim of my study was to explore critical care staff experiences of organ donation following the death of a patient. I would argue that my original research aim has been achieved and I generated enough data to support the thesis findings. The data analysis

process elicited four theoretical categories and I provided a robust analysis of the emerging data.

In order to increase rigour of the grounded theory research, Lincoln and Guba (1985) and Merriam (1998) argue that the ‘dependability’ of the results can be assured through use of three techniques: the investigator’s position, triangulation and audit trail. The thesis opens with a description of personal epistemological views and ontological assumptions. In a systematic way, the thesis progressed to delineate the different processes, phases of inquiry and, more importantly, rationale for the study. Chapter 3 provided a detailed account of methodological approach underpinning the research and Chapter 4 explicated how the data was collected and analysed. Data was collected through use of semi-structured interviews with critical care professionals. Each study participant was encouraged to share their personal and professional experiences thus ensuring data was “*obtained through different sources*” (Zohrabi, 2013; p 259). Chapter 5 provides evidence of my critical thinking through examples of abstract situational mapping, memo writing and focused coding (Charmaz, 2006; Clarke, 2005). Additionally, Chapter 5 provides a strong link between “*the gathered data and my argument*” (Charmaz, 2006; p 182).

Guba and Lincoln (1989) describe ‘transferability’ as the extent to which the findings can be transferred to “*someone interested*” within another care context (p 316). Within Chapter 3, I describe the context of the research setting and sample site. Furthermore, I provide a detailed narrative of the sample characteristics (Section 3.11). Therefore, I am confident that any reader of the thesis will be able to decide on the relevance of the study to their professional role and clinical care setting.

The ‘dependability’ of the study relates to transparency regarding decisions made during the research process. Chapter 4 describes that data analysis process in detail, thus providing a

robust “*inquiry audit trail*” (Lincoln and Guba, 1998; p 317). A collaboration of credibility, transferability and dependability generate the overall ‘confirmability’ of the research. The reflexive approach I adopted during the entire research process, combined with personal critical reflection (6.2), presents a credible and methodically strong research endeavour that produced findings relevant to critical care professionals.

6.6.2 Originality

The findings from the study offer a new and original substantive theory as discussed in Chapter 5. As I outlined within the narrative review of the literature in Chapter 2, critical care staff experiences of organ donation following the death of a patient is a poorly understood phenomenon. My research has provided an original contribution of new knowledge, combined with innovative recommendations for practice. The thesis contests that *fear*, as experienced by critical care staff, is a critical feature that influences the donation outcome. Oliver (2014) defines originality as “*breaking into untried territory*” (p 183) and my research has illuminated a poorly understood area of nursing practice. Charmaz (2006) asks whether the categories are “*fresh*” (p 182) and my conceptual framework, generated by detailed analysis of four theoretical categories, offers an original insight and new knowledge. The thesis findings suggest that addressing each element of *fear* during the donation process will result in a positive donation outcome.

6.6.3 Resonance

Charmaz (2006) advises that the principle underpinning resonance is whether the researcher draws on “*links between larger collectivities or institutions and individual lives, when the*

data so indicate” (p 183). As discussed in Chapter 4, the research methodology I selected sought to give “fullness” to the experiences of critical care staff within their “world” [critical care] (Charmaz, 2006). I concur with Blumer (1969) who suggests that *meaning* is derived from a process of interpretation. In a similar way, some critical care professionals experience *fear* at each stage of the donation process which, I argued, determines the outcome of each situation.

The constant comparative method underpinning my study promoted deep engagement into the experiences of critical care staff. This enabled me to reflexively consider the data for meaning. Additionally, resonance relates to the extent the research “*makes sense*” to participants or people who share their experiences (Charmaz, 2006; p 183). The process of sharing experiences, combined with abductive reasoning, has allowed me to *co-construct reality* and develop meaningful recommendations for practice (Charmaz, 2006).

6.6.4 Usefulness

Charmaz (2006) suggests the usefulness of research is whether it offers “*interpretations that people can use in their everyday worlds*” (page 183). My recommendations for practice derive from the analytical process outlined in Chapter 4. The four theoretical categories generated the core category entitled ‘*fear*’ and the conceptual framework (Figure 14) suggested tacit implications for practice (Charmaz, 2006). The analytical process produced a number of recommendations for practice combined with recommendations for further research. In particular, the recommendation for further research relating to use of alternative teaching strategies to combat the *fear* of mutilation could form part of post-doctoral study. Findings outlined in Chapter 5 suggest that *fear* was a shared phenomenon and resonant amongst critical care professionals. The knowledge gained from this study is useful to

facilitate service improvement and for consideration to in how critical care professionals interact with organ donation when caring for dying patients.

6.7 Conclusion

This study was predicated on the fact that, on average, three people die every day in the UK waiting for an organ transplant (NHSBT, 2017). Additionally, the relative refusal rate for organ donation is around 40%. Some of the reasons are known why relatives decline the option of organ donation (Sque *et al*, 2008), but it is unknown how critical care professionals influence donation discussions and outcomes. Therefore this study sought to explore critical care staff experiences of approaching relatives for organ donation following the death of a patient. The findings from the study indicate that fear is a recurring phenomenon at each stage of the organ donation process. Furthermore, the findings indicate that a *fearful* nursing and medical team contribute towards the potential for suboptimal donation outcomes. I argue that a workforce that is fearful, is a workforce that lacks ability to proactively respond to the challenge of a 40% relative refusal rate. Furthermore, findings within the thesis suggest that current critical care educational strategies are ineffective at removing the *fear* associated with organ donation. Educational strategy is focused on the need for more organ donors but fails to respond to the moral distress and anxiety experienced by some critical care professionals. Critical care professionals appear to be aware of the need for more organ donors but some are restricted by the inherent *fear* of causing harm and distress. The predominant discourse within the thesis is *fear*.

Constructing the grounded theory has been challenging, but I maintain that the new knowledge has greater reward for patient's waiting for transplant than any personal or professional challenge. If nurses and doctors working in critical care confront personal and

professional fear, I am confident the result will be more organs available for use in transplant operations.

Reference List

Academy of Medical Royal Colleges (2008). A code of practice for the diagnosis of death. PPG Design and Print Ltd.

Barber K, Falvey S, Hamilton C, and Collett D, (2006). Potential for organ donation in the UK: an audit of intensive care records. *British Medical Journal*, Vol 332: pp 1124-1127.

Baillie L, and Black S, (2015). Professional Values in Nursing. CRC Press: Taylor and Francis Group.

Bandura A, (1977). Social Learning Theory. Prentice-Hall, New Jersey.

Barbalet JM, (1998). Emotion, Social Theory, and Social Structure: A Macrosociological Approach, Cambridge: Cambridge University Press.

Barnard C, (1968). Human cardiac transplantation. An evaluation of the first two operations performed at the Groote Schuur Hospital, Cape Town. *American Journal of Cardiology*. Vol 22, pp 584-96.

Beauchamp TL, and Childress JF, (1994). Principles of Biomedical Ethics, 4th Edition. New York: Oxford University Press.

Beecher HK, (1968). After the 'definition of irreversible coma'. *New England Journal of Medicine*. 281: pp 1070-1.

Bell MDD, Moss E, and Murphy PG, (2004). Brainstem death testing in the UK – time for reappraisal? *British Journal of Anaesthesia*. Vol 91(5), pp 633-640.

Benner P, (1982). From Novice to Expert. *American Journal of Nursing*. Vol 82, pp 402-7.

Berger P, and Luckmann T, (1991). *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Penguin Books Ltd, London.

Berntzen H, and Björk IT, (2014). Experiences of donor families after consenting to organ donation: A qualitative study. *Intensive and Critical Care Nursing*. Vol 30, pp 266-274.

Birks M, and Mills J, (2011). *Grounded Theory: A Practical Guide*. Sage Publications, London.

Bleakley G, (2017). Understanding Brainstem Death Testing. *British Journal of Neuroscience Nursing*. Vol 14 (4), pp 172-177.

Bleakley G, (2010). Implementing minimum notification criteria for organ donation in an acute hospital's critical care units. *Nursing in Critical Care*. Vol 15 (4), pp 185-191.

Blumer H, (1969). *Symbolic Interactionism: Perspectives and Methods*. University of California Press, Berkeley, Los Angeles.

Bok S, (1989). *Secrets: On the ethics of concealment and revelation*. Vintage Books, New York.

Bowen GA, (2008). Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research*. Vol 8(1), pp 137-152.

British Medical Association (2014). Access to health records: Guidance for health professionals in the United Kingdom. Available at:

[file://nask.man.ac.uk/home\\$/accesstohealthrecords_aug2014.pdf](file://nask.man.ac.uk/home$/accesstohealthrecords_aug2014.pdf)

[Accessed 12/1/18].

Bryant A, and Charmaz K, (2007). The SAGE Handbook of Grounded Theory. Sage Publications Ltd, London.

Burns D, (2015). Foundations of Adult Nursing. Sage Publications.

Caldwell K, Henshaw L, and Taylor G, (2005). Developing a framework for critiquing health research. *Journal of Health, Social and Environmental Issues*. Vol 6, No 1.

Cameron F, and Brownie S, (2010). Enhancing resilience in registered aged care nurses. *Australasian Journal on Aging*. Vol 29 (2), pp 66-71.

Cantwell M, and Clifford C (2000). English nursing and medical students' attitudes towards organ donation. *Journal of Advanced Nursing*. Vol 32(4), pp 961-968.

Centre for Reviews and Dissemination (CRD 2001). CRD's guidance for undertaking reviews in healthcare. Available at:

https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf

[Accessed 9/12/16].

Charmaz K, (2000). Constructivist and objectivist grounded theory. Handbook of Qualitative research. Second Edition. Thousand Oakes, CA: Sage.

Charmaz K, (2002). Grounded theory: Methodology and theory construction. International encyclopaedia of the social and behavioural sciences. Amsterdam: Pergamon.

Charmaz K, (2006). Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis. Sage publications: London.

Charmaz K, (2014). Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis. London: SAGE.

Charmaz K, and Mitchell RG, (2001). Grounded theory in ethnography . Handbook of Ethnography. London, SAGE.

Citerio G, Cypel M, Dobb G, Dominguez-Gil B, Frontera JA, Greer DM, Manara AR, Shemie SD, Smith M, Valenza F, and Wijdicks EFM, (2016). Organ donation in adults: a critical care perspective. *Intensive Care Medicine*. Vol 42, pp 305-315.

Clarke AE, (2003). Situational analysis: Grounded theory mapping after the postmodern turn. *Symbolic Interaction*, 26, 553-576 *as cited in* Charmaz K, (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Sage publications: London.

Clarke AE, (2005). *Situational Analysis: Grounded Theory After the Postmodern Turn*. Sage Publications, Thousand Oaks.

Cooke M, (2014). The challenges of grounded theory. *Nurse Researcher*. Vol 21(5), pp 6-7.

Cook D, Rucker G, Marshall J, Sjøkvist P, Dodek P, Griffith L, Freitag A, Varon J, Bradley C, Mitchell L, Finfer S, Hamielec C, McMullin J, Weaver B, Walter S, and Guyatt G, (2003). Withdrawal of Mechanical Ventilation in Anticipation of Death in the Intensive Care Unit. *The New England Journal of Medicine*. Vol 349 (12), pp 1123- 1132.

Coombes MA, Addington-Hall J, and Long-Sutthall T, (2012). Challenges in transition from intervention to end of life care in intensive care: a qualitative study. *International Journal of Nursing Studies*. Vol 49, pp 519-527.

Corbin J, and Strauss A, (2008). *Basics of Qualitative Research*. Third Edition. Sage Publications.

Coughlan M, Ryan F, and Cronin P, (2013). *Doing a literature review in nursing, health and social care*. Los Angeles, SAGE.

Craswell G, and Poore M, (2015). *Writing for Academic Success*. Second edition. Sage Publications.

Creswell J, (2007). *Qualitative Inquiry and Research design: Choosing Among Five Approaches*. London, Sage.

Crotty M, (1998). *The Foundations of Social Research: Meaning and Perspectives in the Research Process*. London: Sage.

Data Protection Act (1988). The Stationery Office. Available at: http://www.legislation.gov.uk/ukpga/1998/29/pdfs/ukpga_19980029_en.pdf [Accessed 13/1/17]

Dempsey L, Dowling M, Larkin P, and Murphy K, (2016). Sensitive Interviewing in Qualitative Research. *Research in Nursing and Health*. Vol 39, pp 480-490.

Denzin NK, and Lincoln YS, (2008). *Strategies of Qualitative Research*. Third Edition, Sage Publications, Thousand Oakes CA.

Denzin NK, and Lincoln YS, (2011). Introduction: The discipline and practice of qualitative research. *Handbook of Qualitative Research*, 4th Edition. Thousand Oaks, CA: Sage.

Department of Health (2001). *The Royal Liverpool Children's Enquiry: Report HC12-II*.

Department of Health (2001). *Learning from Bristol: The report into Children's Heart Surgery at Bristol Royal Infirmary*.

Department of Health (2008). *Organs for Transplant: a Report from the Organ Donation Taskforce*.

Department of Health (2011). Governance arrangements for research ethics committees: A harmonised edition. Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213753/dh_133993.pdf

[Accessed 13/1/17].

Department of Health (2017). Available at:
<https://www.gov.uk/government/news/government-announces-consultation-on-organ-donation-opt-out-system>

[accessed 11/1/18].

de Sales T, (2006). A changed life: stories from the field. *Spirituality and Health International*. Vol 7, pp 93-99.

Doran M, (2003). The presence of family during brain stem death testing. *Intensive and Critical Care Nursing*. Vol 20, pp 32-37.

Döşemeci L, Cengiz M, Yılmaz M, and Ramazanoğlu A, (2004). Frequency of Spinal Reflex Movements in Brain-Dead Patients. *Transplantation Proceedings*. Vol 36, pp 17-19.

Draucker CB, Martsof DS, Ross R, and Rusk TB, (2007). Theoretical Sampling and Category Development in Grounded Theory. *Qualitative Health Research*. Vol 17 (8), pp 1137-1148.

Eaves YD, (2001). A synthesis technique for grounded theory data analysis. *Methodological Issues in Nursing Research*. Vol 35(5), pp 654-669.

Eraut M, (2007). Learning from Other People in the Workplace. *Oxford Review of Education*. Vol 33 (4), pp 403-422.

Foucault M, (1982). The Subject and Power. *Critical inquiry*. Vol 8(4), pp 777-795.

Fredriksson L, and Eriksson K, (2003). The Ethics of the Caring Conversation. *Nursing Ethics*. Vol 10(2), pp 139-147.

Frid I, Bergbom-Engberg I, and Haljamäe, (1998). Brain death in ICUs and associated care challenges concerning patients and families. *Intensive and Critical Care Nursing*. Vol 14, pp 21-29.

Furedi F, (2007). The only thing we have to fear is the 'culture of fear' itself. Available at: <https://pdfs.semanticscholar.org/05f2/d2c10381c939a080b12f561a7a4b8ee51024.pdf>

[Accessed 7/2/18].

Gadow S, (1996). Ethical Narratives in Practice. *Nursing Science Quarterly: Practice Applications*. 9:1.

Garside M, and Garside J, (2010). Role of urgent care staff in organ donation. *Emergency Nurse*. Vol 18 (6), pp 28.

Gates MG, Parr MB, and Huguen JE, (2012). Enhancing Nursing Knowledge Using High-Fidelity Simulation. *Journal of Nursing Education*. Vol 51 (1), pp 9-15.

General Medical Council (2010). Treatment and care towards the end of life: good practice in decision making. Available at: http://www.gmcuk.org/Treatment_and_care_towards_the_end_of_life_English_1015.pdf
[48902105.pdf](http://www.gmcuk.org/Treatment_and_care_towards_the_end_of_life_English_1015.pdf)

[Accessed 6/1/17].

Glaser BG, (1978). *Theoretical Sensitivity*. Mill Valley, CA: The Sociology Press.

Glaser BG, (1992). *Basics of grounded theory analysis*. Mill Valley, CA: The Sociology Press.

Glaser BG, (2003). The grounded theory perspective. Mill Valley, California: Sociology Press.

Glaser BG, and Strauss AL, (1965). Awareness of Dying. Aldine Publishing Company, Chicago.

Glaser BG, and Strauss AL, (1967). The discovery of grounded theory. Chicago: Aldine *as cited in* Charmaz K, (2006). Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis. Sage publications: London.

Glaser BG, Strauss AL, (1967). The Discovery of Grounded Theory: strategies for qualitative research. Aldine De Gruyter, New York.

Goldberg GR, Gliatto P, and Karani R, (2011). Effect of a 1-Week Clinical Rotation in Palliative Medicine on Medical School Graduates' Knowledge of and Preparedness in Caring for Seriously Ill Patients. *Journal of the American Geriatrics Society*. Vol 59 (9), pp 1724-1729.

Gray JA, (1987). The psychology of fear and stress. Cambridge University Press. Cambridge.

Grbich C, (1999). Qualitative Research in Health: An Introduction. Sage Publications, London.

Griffin AP, (1983). A philosophical analysis of caring in nursing. *Journal of Advanced Nursing*. Vol 8, pp 289-295.

Guba E, and Lincoln Y, (1982). Epistemology and methodological basis of naturalistic enquiry. *Educational Communication and Technology*, 30 (4): pp 233-52.

Guba EG, and Lincoln YS, (1985). Naturalistic inquiry. Thousand Oaks, California: Sage.

Guba E, and Lincoln Y, (1989). Fourth generation evaluation. Newbury Park, CA: Sage.

Gubrium J, (1988). Analyzing Field Reality. Qualitative Research Methods Series 8. A SAGE Publications.

Gutmann E, (2012). Bitter Harvest. *World Affairs*. Vol 175 (2), pp 49-56.

Hall C, and Ritchie D, (2013). What is Nursing? Third Edition. Sage Publications.

Hardy JD, Webb WR, Dalton ML, and Walker GR, (1963). Lung homotransplantation in man. *Journal of American Medical Association*. 186: pp 1065-74.

Hawes N, (2017). Welsh opt-out law fails to increase organ donations. *British Medical Journal*. Vol 359, published online: <https://doi.org/10.1136/bmj.j5659>

Health Research Authority (2014). Available at:

<http://www.hra.nhs.uk/resources/research-legislation-and-governance/research-governance-frameworks/>

[Accessed 2nd July 2014].

Hendrick J, (2000). Law and Ethics in Nursing and Healthcare. Cheltenham: Nelson Thornes, Ltd. 221.

Hess JD, (2003). Gadwo's relational narrative: an elaboration. *Nursing Philosophy*. Vol 4, pp 137-148.

Higginbottom G, and Lauridsen EI, (2014). The roots and development of constructivist grounded theory. *Nurse Researcher*. Vol 21(5), pages 8-13.

Human Tissue Act (2004). Human Tissue Authority: The regulator for human tissue and organs. <https://www.hta.gov.uk/policies/human-tissue-act-2004>

[Accessed 27/11/16].

Human Transplantation (Wales) Act (2013). Available at:

<http://www.legislation.gov.uk/anaw/2013/5/contents/enacted>

[Accessed 11/1/18].

Intensive Care National Audit and Research Centre (ICNARC, 2014). Key Statistics from the Case Mix Programme 2013-14. Available at:

<https://www.icnarc.org/Our-Audit/Audits/Cmp/Reports/Summary-Statistics>.

[Accessed 22/10/14].

Intensive Care National Audit and Research Centre (2016). Available at:

<https://www.icnarc.org/Our-Audit/Audits/Cmp/Our-National-Analyses/Mortality>.

[Accessed 1/12/16].

Jabareen Y, (2009). Building a Conceptual Framework. *International Journal of Qualitative Methods*. Vol 8 (4), pp 49-62.

Jewson ND, (1976). The disappearance of the Sick-Man from Medical Cosmology 1770-1870. *Sociology*. Vol 10 pp 225-244.

Jones K, (2004). Mission Drift in Qualitative Research, or Moving Toward a systematic Review of qualitative Studies, Moving Back to a More Systematic Narrative Review. *The Qualitative Report*. Vol 9 (1), pp 95-112.

Kaplan D, (2004). *The SAGE Handbook of Qualitative Methodology*. Thousand Oaks: Sage.

Kearl MC, (1996). Dying Well. *American Behavioural Scientist*. Vol 39 (3), pp 336-360.

Key Performance Indicators (2014). North West Organ Donation Services Team – [Accessed 22nd October 2014] (confidential secure database).

Kübler-Ross E, (1969). On Death and Dying. Tavistock Publications, London.

Lee RM, (1993). Doing research on sensitive topics. Thousand Oaks, CA: Sage Publications.

Lemonsky F, (2015). Service user involvement in research. *The Lancet: Psychiatry*. Vol 2 (9), no page number.

Liamputtong P, (2007). Researching the vulnerable: A guide to sensitive research methods. London: Sage Publications.

Linden PK, (2009). History of Solid Organ Transplantation and Organ Donation. *Critical Care Clinics*. Vol 25 (1), pp 165 – 184.

Lloyd-Williams M, Morton J, and Peters S, (2009). The End-of-Life Care Experiences of Relatives of Brain Dead Intensive Care Patients. *Journal of Pain and Symptom Management*. Vol 37 (4), pp 659-664.

Locke K, (2001). Grounded Theory in Management Research. Sage Publications.

Lomero M, Jiménez-Herrera M, Rasero M, and Sandiumenge A, (2017). Nurses' attitudes and knowledge regarding organ and tissue donation and transplantation in a provincial hospital: A descriptive and multivariate analysis. *Nursing and Health Sciences*. Vol 19, pp 322-330.

Lupton D, (1996). Food, the Body and the Self cited in Turner BS, (1996). What is the Sociology of the Body? *Body and Society*. Vol 3 (1), pp 103-107.

Mandan J, Sidhu HS, and Mahmood A, (2016). Should a clinical rotation in hematology be mandatory for undergraduate medical students? *Advances in Medical Education and Practice*. Vol 7, pp 519-521.

Marsh H, (2015). Do No Harm: Stories of Life, Death and Brain Surgery. Weidenfeld and Nicolson.

Marshall B, Cardon P, Poddar A, and Fontenot R, (2013). Does sample size matter in qualitative research? A review of qualitative interviews in IS research. *The Journal of Computer Information Systems*. Vol 54 (1), pp 11-22.

McLoughlin H, (2009). Service-User Research in Health and Social Care. Sage Publishing, London.

Medical Royal Colleges (1979). Diagnosis of death. *Lancet*. 313: pages 261-2.

Menzies-Lyth I, (1960). Social Systems as a Defense Against Anxiety. An empirical Study of the Nursing service of a General Hospital. *Human Relations*, 13: pp 95-121.

Merriam SB, (1998). Qualitative research and case study applications in education. San Francisco: Jossey-Bass.

Meyer K, Bjørk T, and Eide H, (2012). Intensive care nurses' perceptions of their professional competence in the organ donation process: a national survey. *Journal of Advanced Nursing*. Vol68 (1), pp 104-115.

Mills J, Bonner A, and Francis K, (2006). The Development of Constructivist Grounded Theory. *International Journal of Qualitative Methods*. Vol 5 (1), pp 25-34.

Mills J, Bonner A, and Francis K, (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*. Vol 12 (1), pp 8-13.

Moher D, Shamseer L, Clarke M, Ghersi M, Liberati A, Petticrew M, Shekelle P, Stewart LA, and PRISMA-P Group (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P). *Systematic Review*. Vol 4 (1), pp 1-9.

Mollaret P, and Goulon M, (1959). Le coma dépassé (mémoire préliminaire). *Rev Neurol (Paris)*, 101; pp 3-15.

Morse JM, (2009). *Developing Grounded Theory. The Second Generation*. Left Coast Press, Walnut Creek, CA.

Moule P, and Goodman M, (2014). *Nursing research: An Introduction*. Second Edition. Sage, London.

Murphy PG, Bodenham AR, and Thompson JP, (2012). Diagnosis of death and organ donation in 2012. *British Journal of Anaesthesia*. Volume 108, Number (S1), i1-i2.

National Council for Palliative Care (NCPC, 2013). The end of life care strategy: New ambitions. Available at:

http://www.ncpc.org.uk/sites/default/files/End%20of%20Life%20Care%20Strategy%20New%20Ambitions%20Report_WEB.pdf

[Accessed 5/1/17].

National Health Service (NHS, 2012). Organ Donation. Available at:

<http://www.nhs.uk/Conditions/Organ-donation/Pages/Introduction.aspx>.

[Accessed Saturday 15th November 2014].

Neilsen D, (2013). Informed Consent, An Ongoing Conversation. *Narrative Inquiry in Bioethics*. Vol 3 (1), pp E10-E12.

NHS Blood and Transplant (2017). Transplant Activity Report. Available at:
<https://www.organdonation.nhs.uk/supporting-my-decision/statistics-about-organ-donation/transplant-activity-report/>

[Accessed 23/10/17 and 12/1/18].

NHS Blood and Transplant (2016). Transplant Activity Report. Available at:
<http://www.odt.nhs.uk/uk-transplant-registry/annual-activity-report/>

[Accessed 27/11/16].

National Institute for Health and Care Excellence (NICE, 2011). Clinical Guidance 135: Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. <https://www.nice.org.uk/guidance/cg135> [Accessed 27/11/16].

NHS Blood and Transplant (2015). Organ Donation: transplantation milestones.
http://www.organdonation.nhs.uk/about_transplants/transplantation_milestones/index.asp

[Accessed 2nd January 2015].

NHS Blood and Transplant (2013). Holby City ‘scared off organ donors’, doctor’s claim. Available at:

<http://www.bbc.co.uk/news/entertainment-arts-23575817>

[Accessed 3/9/17].

NHS Blood and Transplant (2012). Available at:

<http://www.odt.nhs.uk/donation/deceased-donation/donation-after-circulatory-death/>

[Accessed Saturday 15th November 2014].

Nizza IE, Britton HP, and Smith JA, (2016). ‘You have to die first’: Exploring the thoughts and feelings on organ donation of British women who have not signed up to be donors. *Journal of Health Psychology*. Vol 21 (5), pp 650-660.

Nursing and Midwifery Council (NMC, 2015). *The Code: professional standards of practice and behaviour for nurses and midwives*. London: NMC.

Ochieng J, Buwembo W, Ibingira C, Kiryowa H, and Nzarubara G, (2015). Informed consent in clinical practice: patients' experiences and perspectives following surgery. *BioMed Central*. Vol 8:765, pp 1-6.

Office for National Statistics (2015).

<http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015>.

[Accessed Friday 6th March 2015].

Office for National Statistics (2016).

<http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015>

[Accessed 1/12/16].

Oliver. P, (2014). *Writing Your Thesis*. 3rd edition. Sage, London.

Olthuis G, Dekkers W, Leget C, and Vogelaar P, (2006). The caring relationship in hospice care: An analysis based on the ethics of the caring conversation. *Nursing Ethics*. Vol 13 (1), pp 29-40.

Oróy A, Strómskag K E, Gjengedal E, (2015). Do we treat individuals as patients or as potential donors? A phenomenological study of healthcare professionals' experiences. *Nursing Ethics*. Vol 22(2), pp 163-175.

Oróy A, Strómskag K E, Gjengedal E, (2013). Approaching Families on the Subject of Organ Donation: A Phenomenological Study of the Experience of Healthcare Professionals. *Intensive and Critical Care Nursing*. 29 (1), pp 202 - 211.

Parahoo K, (2006). *Nursing Research: Principles, Process and Issues*. Second Edition. Palgrave, Macmillan.

Pearson A, Robertson-Malt S, Walsh K, and Fitzgerald M, (2001). Intensive care nurses' experience of caring for brain dead organ donor patients. *Journal of Clinical Nursing*. Vol 10, pp 132-139.

Polit DF, and Beck CT, (2014). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Eighth Edition, Lippincott Williams and Wilkins.

Polit D, and Beck C, (2010). *Essentials of nursing research: Appraising evidence for nursing practice*, 7th Edition. London, Lippincott Williams & Wilkins.

Powner DJ, Darby MD, Joseph M, (1999). Current Considerations in the Issue of Brain Death. *Neurosurgery Online*. Vol 45 (5), page 1222.

Public Health Resource Unit (2006). *Critical appraisal Skills Programme (CASP)*. Ten questions to make sense of qualitative research.

Reitz BA, Wallwork JL, and Hunt SA, (1982). Heart-lung transplantation: a successful therapy for patients with pulmonary vascular disease. *New England Journal of Medicine*. 306: pp 557-64.

Richards L, (2015). *Handling Qualitative Data: A Practical Guide*. Sage Publications.

Ricoeur P, (1995). *Het problem van de grondslagen van de moral*. (The problem of the foundations of morality). Kampen: Kok Agora: 33 cited in Olthuis G, Dekkers W, Leget C, and Vogelaar P, (2006). The caring relationship in hospice care: An analysis based on the ethics of the caring conversation. *Nursing Ethics*. Vol 13 (1), pp 29-40.

Ross D, (1968). Report of a heart transplant operation. *American Journal of Cardiology*. 22, pp 838-9.

Rumrill PD, Fitzgerald SM, and Merchant WR, (2010). Using scoping literature reviews as a means of understanding and interpreting existing literature. *Work*. Vol 35 (3), pp 399-404.

Russell H, and Ryan, (2010). *Analyzing Qualitative Data: Systematic Approaches*. Sage Publications.

Saks M, and Allsop J, (2013). *Researching Health. Qualitative, Quantitative and Mixed Methods*. Sage Publications.

Salehi S, Kanani T, and Abedi H, (2013) Iranian nurses' experiences of brain dead donors care in intensive care units: a phenomenological study. *Iranian Journal of Nursing and Midwifery Research*. Vol 18(6), pp 475-482.

Sapsford R, and Jupp V, (2006). *Data Collection and Analysis. Second Edition*. Sage Publications, London.

Seale C, (2009). Hastening death in end of life care: A survey of doctors. *Social Science and Medicine*. Vol 69, pp 1659-1666.

Shaw R, (2010). Perceptions of the gift relationship in organ and tissue donation: Views of intensivists and donor and recipient coordinators. *Social Science and Medicine*. Vol 70, pp 609-615.

Skott C, (2003). Storied Ethics: Conversations in Nursing Care. *Nursing Ethics*. Vol 10 (4), pp 368-376.

Smith M, (2012). Brain death: time for an international consensus. *British Journal of Anaesthesia*. 108 (s1): i6 – i9.

Smith NJ, (2009). *Achieving your Professional Doctorate*. Open University Press, McGraw-Hill Education.

Speziale HJ, and Carpenter DR, (2003). *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Third Edition, Lippincott Williams and Wilkins.

Sque M, Long T, Payne S, and Allardyce D, (2006). Exploring the end of life decision-making and hospital experiences of families who did not donate organs or tissues for transplant operations. *Journal of Advanced Nursing*. Vol 61(2), pp 134-144.

Sque M, Long T, Payne S, and Allardyce D, (2008). Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'? *Journal of Advanced Nursing*. Vol 61(2), pp 134-144.

Starzl TE, Marchioro TL, and Huntley RT, (1964). Experimental and clinical homotransplantation of the liver. *Ann N Y Acad Sci*, 120, pp 739-65.

St Ledger U, Begley A, Reid J, Prior L, McAuley D, and Blackwood B, (2012). Moral distress in end of life care in the intensive care unit. *Journal of Advanced Nursing*. Vol 69 (8), pp 1869-1880.

Stern PN, (2009). In the beginning Glaser and Strauss created grounded theory. In Morse JM, Stern PN, and Corbin J. *Grounded Theory. The Second Generation*. Left Coast Press, Walnut Creek, CA.

Strauss AL, (1987). *Qualitative analysis for social scientists*. New York: Cambridge University Press.

Strauss AL, and Corbin J, (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Stroud R, (2002). The withdrawal of life support in adult intensive care: an evaluative review of the literature. *Nursing in Critical Care*, Vol 7(4), pp 176-184.

Streat S, (2004). Clinical review: Moral assumptions and the process of organ donation in the intensive care unit. *Critical Care*. Vol 8 (5), pp 382-388.

Templeman J, (2015). An ethnographic study of critical care nurses' experiences following the decision to withdraw life-sustaining treatment from patients in a UK intensive care unit. *Professional Doctorate Thesis*. University of Salford. Available at: <http://usir.salford.ac.uk/36188/1/Prof%20Doc%20thesis%20%28final%20version%202015%29.pdf>

[Accessed 22/11/17].

Timmermans S, and Tavory I, (2016). Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis. *Sociological Theory*. Vol 30 (3), pp 167-186.

Tudor A, (2003). A (macro) sociology of fear? *The Sociological Review*. Vol 51 (2), pp 238-256.

Turner BS, (1996). What is the Sociology of the Body? *Body and Society*. Vol 3 (1), pp 103-107.

Wace J, and Kai M, (2000). Anaesthesia for organ donation in the brainstem dead. *Anaesthesia*. Vol 55, Issue 6, page 590.

UK Transplant Registry (2015). http://www.odt.nhs.uk/uk-transplant-registry/slides_to_download/

[Accessed 2nd January 2015].

Uniform Declaration of Death Act (1981). Available at:

http://pntb.org/wordpress/wp-content/uploads/Uniform-Determination-of-Death-1980_5c.pdf

[Accessed Friday 6th March 2015].

Valentine CW, (1930). The innate basis of fear. *Journal of Genetic Psychology*. Vol 37, pp 394-419.

Verble M, and Worth J, (1999). Dealing with the fear of mutilation in the donation discussion. *Journal of Transplant Coordination*. Vol 9 (1), pp 54-56.

Vijayalakshmi P, Nagarajaiah, Ramachandra, and Bada Math S, (2015). Indian ICU nurses' perceptions of and attitudes towards organ donation. *British Journal of Nursing*. Vol 24 (13), pp 694-697.

Warnock C, Buchanan J, and Tod A, (2017). The difficulties experienced by nurses and healthcare staff involved in the process of breaking bad news. *Journal of Advanced Nursing*. doi: 10.1111/jan.13252

Watson CJE, and Dark JH, (2012). Organ transplantation: historical perspective and current practice. *British Journal of Anaesthesia*, 108 (S1): i29-i42.

Wellington J, Bathmaker A, Hunt C, McCulloch G, and Sikes P, (2012). *Succeeding with Your Doctorate*. Sage Publications.

Wheeler MS, O'Friel M, and Cheung AHS, (1994). Cultural beliefs of Asian-Americans as barriers to organ donation. *Journal of Transplant Coordination*. Vol 4 (3), pp 146-150.

White G, (2003). Intensive care nurses' perceptions of brain death. *Australian Critical Care*. Vol 16 (1), pp 7-14.

Young PJ, and Matta BF, (2000). Anaesthesia for organ donation in the brainstem dead – why bother? *Anaesthesia*. Vol 55 (2), pp 105-106.

Zampieron A, Corso M, and Frigo AC, (2010). Undergraduate nursing students' attitudes towards organ donation: a survey in an Italian university. *International Nursing Review*. pp 370-376.

Zohrabi M, (2013). Mixed Method Research: Instruments, Validity, Reliability and Reporting Findings. *Theory and Practice in Language Studies*. Vol 3 (2), pp 254-262.

Zwart H, (2014). The donor organ as an 'object a': a Lacanian perspective on organ donation and transplantation medicine. *Medicine, Healthcare and Philosophy*. Vol 17 (4), pp 559-571.

List of Appendices

Appendix 1: Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA)

Appendix 2: Screen shots of literature search strategy (CINAHL, British Nursing Index and Medline 2000 – 2017)

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Appendix 4: United Kingdom potential deceased donor population

Appendix 5: Proportion of people who opted-in on the NHS Organ Donor Register

Appendix 6: Ethical Approval (University of Salford)

Appendix 7: Ethical Approval (Hospital Trust)

Appendix 8: Ethical Approval (Hospital Trust)

Appendix 9: Invitation Letter and Participant Information Sheet

Appendix 10: Interview Schedule

Appendix 11: Participant Consent Form

Appendix 12: Final letter following Research Scholarship Award 2015-16

Appendix 13: Iterative process of data collection and analysis

Appendix 1: Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Moher *et al*, 2009)

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	

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Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	

Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

Appendix 2: Screen shots of literature search strategy (CINAHL, British Nursing Index and Medline (2000 – 2017)

The screenshot displays a web-based search interface with the following components:

- Browser and Navigation:** The address bar shows the URL <http://web.a.ebscohost.com/salford.idm.oclc.org/ehost/resultsadv>. The page title is "Result List: organ donation ...".
- Search Controls:** Buttons for "Select / deselect all", "Search with AND", "Search with OR", "Delete Searches", and "Refresh Search Results" are visible.
- Search Results Table:**

Search ID#	Search Terms	Search Options	Actions
S2	organ donation AND intensive care AND experience	Limiters - Published Date: 20060101-20151231 Search modes - Boolean/Phrase	View Results (25) View Details Edit
S1	organ donation AND intensive care AND experience	Search modes - Boolean/Phrase	View Results (32) View Details Edit
- Refine Results Panel (Left):**
 - Current Search:** Boolean/Phrase: organ donation AND intensive care AND experience; Limiters: Published Date: 20060101-20151231.
 - Limit To:**
 - Linked Full Text
 - References Available
 - Abstract Available
 - Publication Date: 2008 to 2015
 - Source Types:**
 - All Results
 - Academic Journals (23)
 - Dissertations (1)
 - Subject: Major Heading**
 - Publisher**
 - Publication**
- Search Results (1 - 10 of 25):**
 - Indian ICU nurses' perceptions of and attitudes towards organ donation.**
 (includes abstract) Vijayalakshmi, Poreddi, Nagarajaiah, Ramachandra, Math, Suresh Bada; British Journal of Nursing, 7/9/2015; 24(13): 694-697. 4p. (Journal Article - research, tables/charts) ISSN: 0966-0461
Subjects: Critical Care Nursing; Intensive Care Units; Organ Procurement; Nurse Attitudes; Nursing Role; Adult; 19-44 years; Middle Aged: 45-64 years; Aged 65+ years; Female; Male
 Academic Journal | Cited References: (1)
 - Attitudes towards organ donor advocacy among Swedish intensive care nurses.**
 (includes abstract) Forsberg, Anna; Lennerling, Annette; Fridh, Isabell; Rizell, Magnus; Lovén, Charlotte; Flodén, Anne; Nursing in Critical Care, May2015; 20(3): 126-133. 8p. (Journal Article - research, tables/charts) ISSN: 1362-1017 PMID: 25611200
Subjects: Transplant Donors Sweden; Patient Advocacy; Critical Care Nursing Sweden; Nurse Attitudes; Adult: 19-44 years; Middle Aged: 45-64 years; Aged 65+ years; Female; Male
 Academic Journal | Cited References: (24) Times Cited in this Database: (1) | PlumX Metrics
 - Indian nurses' perceptions of and attitudes towards organ donation...This article was originally published in the British Journal of Nursing 24(13): 694 -7**
 (includes abstract) Vijayalakshmi, Poreddi, Nagarajaiah, Ramachandra, Math, Suresh Bada; British Journal of Neuroscience Nursing, Aug/Sep2015; 11(4): 188-190. 3p. (Journal Article - research, tables/charts) ISSN: 1747-0307
Subjects: Perception; Nurse Attitudes; Organ Procurement India; Adult: 19-44 years; Middle Aged: 45-64 years; Female; Male
 Academic Journal
 - Approaching families on the subject of organ donation: A phenomenological study of the experience of healthcare professionals.**
 (includes abstract) Oraya, Aud; Strömskag, Kjell Erik; Gjengedal, Eva; Intensive & Critical Care Nursing, 2013; 29(4): 202-211. 10p. (Journal Article - research) ISSN: 0964-3397 PMID: 23540726
Subjects: Organ Procurement; Professional-Family Relations; Attitude of Health Personnel; Adult: 19-44 years; Middle Aged: 45-64 years; Male; Female
 Academic Journal | Cited References: (44) | PlumX Metrics
 - The organ donation process: a humanist perspective based on the experience of nursing care.**
 (includes abstract) ... Oct2012; 13(4): 295-301. 7p. (Journal Article) ISSN: 1466-7681 PMID: 22950733
Subjects: Organ Procurement; Professional-Family Relations; Attitude of Health Personnel; Adult: 19-44 years; Middle Aged: 45-64 years; Male; Female
 Academic Journal | Cited References: (44) | PlumX Metrics

Your search for **organ donation + intensive care + experience** found no results.
Below are suggested results for **organ donation + intensive care + experience**.

12 Results

Search within Cite Email Print Save

Relevance

Select 1-12 0 Selected Items Brief view Detailed view

Narrow results

Peer reviewed

Publication date

2012 - 2015 (years)

Enter a date range Hide
(Valid formats: yyyy-mm-dd, yyyy-mm, yyyy)

Starting:

Ending:

Author

Publication title

1 The **organ donation** process: a humanist perspective based on the **experience** of nursing care
Monforte-Royo, Cristina; Roqué, MaVictoria. *Nursing Philosophy* 13.4 (October 2012): 295-301.
...increasingly common in **intensive** care units (ICUs)
...are potential **organ** donors. **Intensive** care units use
...suitable multi-**organ** donors for people
Cited by (3)
Abstract/Details Preview

2 Approaching families on the subject of **organ donation**: A phenomenological study of the **experience** of healthcare professionals
Orøy, Aud; Strømskag, Kjell Erik; Gjengedal, Eva. *Intensive and Critical Care Nursing* 29.4 (August 2013): 202-211.
...when approaching the subject of **organ donation**. A hermeneutic phenomenological
...hospital chaplains recruited from two **intensive** care units (ICUs) in a Norwegian
...approach families on the subject of **organ donation**. [Publication] 48 references
Cited by (3) References (57)
Abstract/Details Preview

3 Indian ICU nurses' perceptions of and attitudes towards **organ donation**
Vijayalakshmi, Poreddi; Math, Suresh Bada; Nagarajiah Jo 2; Ramachandra Jo 3. *British Journal of Nursing* 24.13 (July 9, 2015): 694-697.
...of them actually 'signed the **organ donation** card'. There were significant
...between intentions to sign the **organ donation** card and gender (xsup 2 = 5.852
...xsup 2 = 40.175; p 0.000), and **experience** caring for brain-dead patients
Abstract/Details Preview

4 The core of after death care in relation to **organ donation** - A grounded theory study
Forsberg, Anna; Flodén, Anne; Lennerling, Annette; Karlsson, Veronika; Nilsson, Madeleine; et al. *Intensive and Critical Care Nursing* 30.5 (October 2014): 275-282.
...how **intensive** and critical care nurses **experience** and deal with after
...thereby a possible **organ** donor, to the time
...achieving a basis for **organ donation** through dignified
References (32)
Abstract/Details Preview

14:26
19/04/2016

[New Search](#) | [MeSH 2016](#) | [Publications](#) | [Indexes](#) | [Sign In](#) | [Folder](#) | [Preferences](#) | [Languages](#) | [Help](#)

Searching: **MEDLINE** | [Choose Databases](#)
 [Suggest Subject Terms](#)

[Select a Field \(optional\)](#) [Search](#) [Clear](#) [?](#)
 AND [Select a Field \(optional\)](#)
 AND [Select a Field \(optional\)](#) [+](#) [-](#)

[Basic Search](#) | [Advanced Search](#) | [Search History](#)

Search History/Alerts
[Print Search History](#) | [Retrieve Searches](#) | [Retrieve Alerts](#) | [Save Searches / Alerts](#)

[Select / deselect all](#) | [Search with AND](#) | [Search with OR](#) | [Delete Searches](#) | [Refresh Search Results](#)

Search ID#	Search Terms	Search Options	Actions
<input type="checkbox"/> S2	organ donation AND intensive care AND experience	Limiters - Date of Publication: 20060101-20161231 Search modes - Boolean/Phrase	View Results (45) View Details Edit
<input type="checkbox"/> S1	organ donation AND intensive care AND experience	Search modes - Boolean/Phrase	View Results (72) View Details Edit

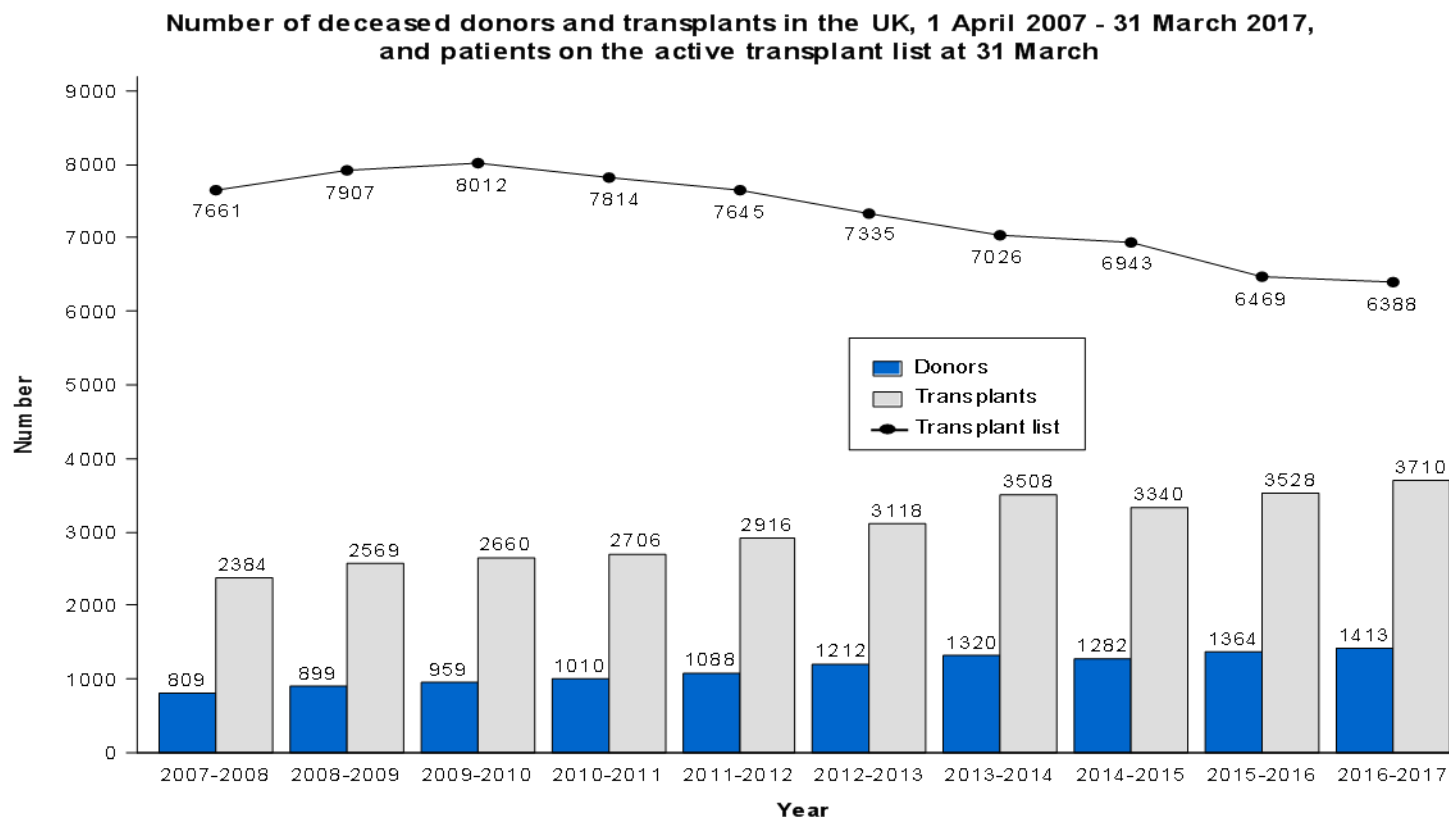
Refine Results | **Search Results: 1 - 10 of 45** | [Relevance](#) | [Page Options](#) | [Share](#)

Current Search
 Boolean/Phrase:
 organ donation AND intensive care AND experience
 Limiters
 Date of Publication: 20060101-20161231
 Limit To
 [Linked Full Text](#)
 [Abstract Available](#)
 [English Language](#)
 2006 [Publication Date](#) 2016

- Contribution of the ethics committee of the French society of intensive care medicine to a scenario for the implementation of organ donation after Maastricht III-type cardiac death in France.**
 (English) ; Abstract available. By: Graftieux JP, Boltaert PE, Haddad L, Kentish-Barnes N, Nitenberg G, Robert R, Villers D, Dreyfuss D; ethics committee of the SRLF, Annales Françaises D'anesthésie Et De Réanimation [Ann Fr Anesth Reanim], ISSN: 1769-6623, 2014 Feb; Vol. 33 (2), pp. 128-34; Publisher: Elsevier; PMID: 24462574
 Subjects: France, Critical Care; Ethics Committees; Heart Arrest; Societies, Medical; Terminal Care ethics; Tissue Donors classification; Tissue and Organ Procurement ethics
[Academic Journal](#) | [Full Text](#)
- The organ donation process: a humanist perspective based on the experience of nursing care.**
 (English) By: Monforte-Royo C; Roqué MV, Nursing Philosophy; An International Journal For Healthcare Professionals [Nurs Philos], ISSN: 1466-769X, 2012 Oct; Vol. 13 (4), pp. 295-301; Publisher: Wiley; PMID: 22950733
 Subjects: Nursing Care ethics; Nursing Staff; Hospital psychology; Personhood; Tissue and Organ Procurement organization & administration
[Academic Journal](#) | [PDF Full Text](#)
- Attitudes towards organ donor advocacy among Swedish intensive care nurses.**
 (English) ; Abstract available. By: Forsberg A, Lennerling A, Fridh I, Rizell M, Lovén C, Flodén A, Nursing In Critical Care [Nurs Crit Care], ISSN: 1478-5153, 2015 May; Vol. 20 (3), pp. 126-33; Publisher: Wiley; PMID: 25611200
[Academic Journal](#)

14:29
 19/04/2016

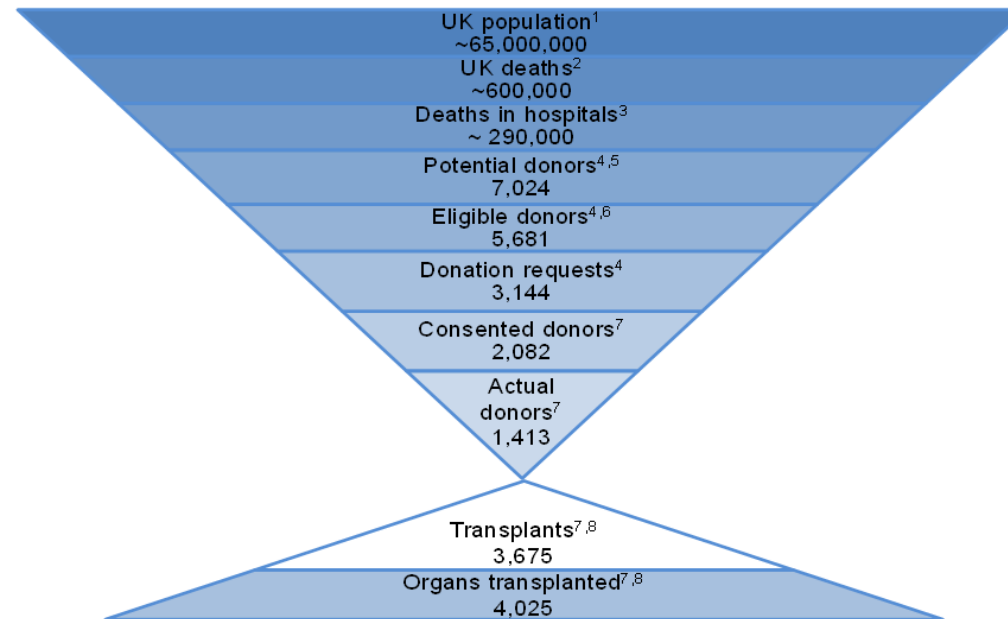
Appendix 3: Number of deceased donors and transplants in the United Kingdom (1st April 2007 – 31st March 2017)



Source: Transplant activity in the UK, 2016-2017, NHS Blood and Transplant

Appendix 4: United Kingdom potential deceased organ donor population (1st April 2007 – 31st March 2017)

UK potential deceased organ donor population, 1 April 2016 – 31 March 2017



¹ Mid 2015 estimates: www.ons.gov.uk

² 2015 data: England & Wales www.ons.gov.uk; Scotland www.gro-scotland.gov.uk; Northern Ireland www.nisra.gov.uk

³ 2015 data: England & Wales www.ons.gov.uk; Scotland www.isdscotland.org; Northern Ireland www.nisra.gov.uk

⁴ 2016/2017 data: NHSBT, Potential Donor Audit

⁵ Potential donor - patients for whom death was confirmed following neurological tests or patients who had treatment withdrawn and death was anticipated within four hours

⁶ Eligible donor - Potential donor with no absolute medical contraindications to solid organ donation

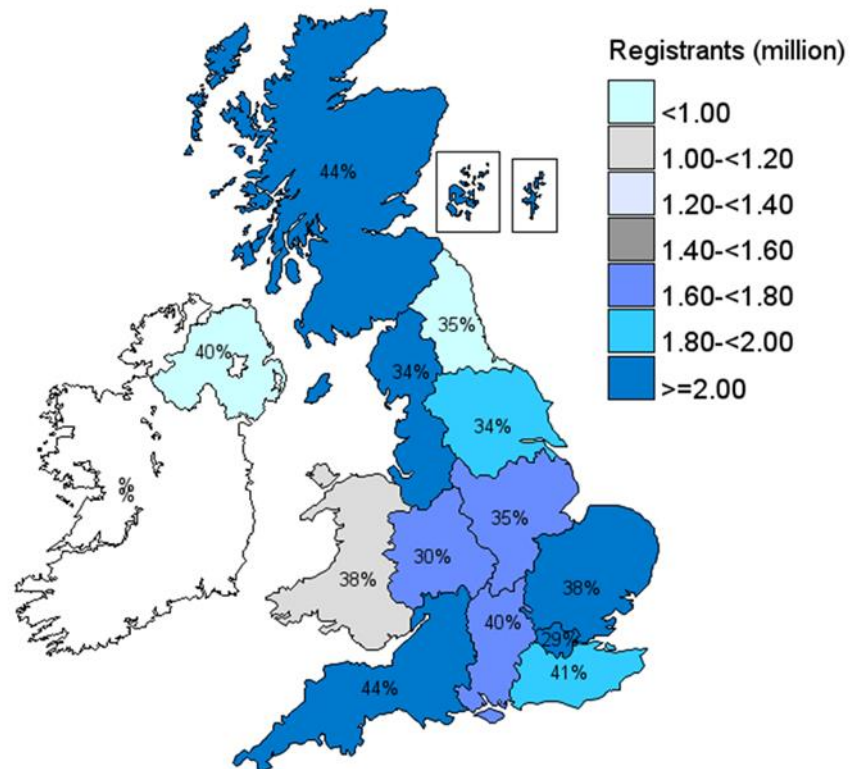
⁷ 2016/2017 deceased donor data: NHSBT, UK Transplant Registry

⁸ Using organs from actual donors in the UK

Source: Transplant activity in the UK, 2016-2017, NHS Blood and Transplant

Appendix 5: Proportion of people who opted-in on the NHS Organ Donor Register

Proportion of people who opted-in on the NHS Organ Donor Register by 31 March 2017, by Strategic Health Authority



Source: Transplant activity in the UK, 2016-2017, NHS Blood and Transplant

Appendix 6: Ethical Approval (University of Salford)



Research, Innovation and Academic
Engagement Ethical Approval Panel

College of Health & Social Care
AD 101 Allerton Building
University of Salford
M6 6PU

T +44(0)161 295 2280
HSresearch@salford.ac.uk

www.salford.ac.uk/

2 June 2015

Dear Greg,

RE: ETHICS APPLICATION HSCR 15-43 – What engages critical care staff to consider engaging with relatives about organ donation following end of life decisions?

Based on the information you provided, I am pleased to inform you that application HSCR15-43 has been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible by contacting HSresearch@salford.ac.uk

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Sue McAndrew'.

Sue McAndrew
Chair of the Research Ethics Panel

Appendix 7: Ethical Approval (Hospital Trust)

20th April 2015

Gregory Bleakley
Senior Lecturer in Adult nursing
Bolton University
Faculty of Wellbeing and Social Sciences
Deane Road
Bolton
BL3 5AB

Dear Greg,

Professional Doctorate Project: What influences critical care staff to engage with relatives about organ donation following end of life decisions?

Further to our recent correspondence and following review of the above named project, I can confirm that the project is approved by the NHSBT R&D Office. This approval is granted on the basis that your project continues to be supported in principle by NHSBT Organ Donation and Transplantation (ODT) colleagues.

Dr James Neuberger (Associate Medical Director) has suggested an honorary contract be provided and the R&D Office will organise this separately. A member of the R&D Office team shall be in touch shortly to make the necessary arrangements.

If you have any questions relating to this approval please contact the NHSBT R&D Office (research.office@nhsbt.nhs.uk) quoting the Reference Number: UG15-02.

Yours sincerely,



Dr Nick Watkins
Assistant Director – Research & Development

cc: Anthony Clarkson, ODT
James Neuberger, ODT

Appendix 8: Ethical Approval (Hospital Trust)

Greg Bleakley
Senior Lecturer in Adult Nursing and Health
University of Bolton
Deane Road
Bolton
BL3 5AB

Ref: R03863-Ltr 24a-Greg Bleakley

Dear Mr Bleakley,

PIN: R03863 (Please quote this number in all future correspondence)
Research Study: A qualitative inquiry into the experiences of critical care staff and organ donation

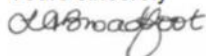
Further to the above study being registered with Central Manchester University Hospitals NHS Foundation Trust, I can confirm that the study documentation received and listed in the table below, has now been reviewed and ethical approval is not required in accordance with the new GAFREC guidelines.

We acknowledge that the University of Salford will act as the sponsor for this study.

I am pleased to confirm that the Clinical Director of Adult Intensive Care and the Manchester Royal Infirmary has given approval for the project to be undertaken.

The Trust aims for its research projects to recruit their first participant within 30 days of the recruitment start date. If you do not tell us your actual recruitment start date, we will use this approval date. This information is important for monitoring Trust recruitment performance for internal and external assessment. I would like to take this opportunity to wish you well with your research.

Yours sincerely



Lorraine Broadfoot
Research Operations Manager

12th June 2015

Date:.....

cc. Sarah Leo

Appendix 9: Invitation Letter and Participant Information Sheet



Date:

Dear

Critical Care Unit / Emergency Department

Manchester Royal Infirmary

Oxford Road

Manchester

M13 9WL

Dear

This is an invitation for you to take part in a research study that aims to explore the experiences of critical care staff conversations about end of life decisions in relation to the organ donation request.

In The United Kingdom (UK), despite recent strategies to improve consent rates to organ donation, the number of families that actually consent to organ donation remains fixed at 60%. That is, 40% of relatives / carers decline the option of organ donation when asked. The work in this area is particularly challenging for for critical care staff and it is recognised that their input is essential in securing consent. Hence, it is important to understand the experiences of critical care staff so that best ways of engaging with potential donor families can be established.

In particular, the study aims to better understand whether critical care staff experiences influence carer decisions to donate organs for use in transplant operations.

Before you decide whether you would like to take part, you need to be fully informed why this research is being conducted and what you would be required to do. Please take time to read the attached information sheet carefully.

Please contact me on the details above if you would like any further information or help concerning the study .

Yours Sincerely,

Greg Bleakley

Lecturer in Adult Nursing

University of Manchester

Faculty of Medical and Human Sciences

School of Nursing, Midwifery and Social Work

Oxford Road

Manchester

M13 9PL

Tel: 0161

Participant Information Sheet

Study Title: A grounded theory study exploring critical care staff experiences of approaching relatives for organ donation following the death of a patient?

Invitation

This is an invitation for you to take part in a research study that aims to explore carer decisions to donate organs for use in transplant operations. In particular, the study aims to investigate whether critical care staff experiences, attitudes and behaviour influences carer decisions to donate organs. Before you consider taking part in the study, it is important that you understand why the research is being conducted and what it would involve for you. Please take time to read the following information carefully. If you have any further questions or what you read in not clear, I will offer the opportunity to discuss these questions in more detail. Take time to decide whether or not to take part.

Brief Summary

In the United Kingdom there are approximately 10,000 patients waiting for a life saving organ transplant. These patients often wait for months, even years, for their transplant and sadly some patients will die whilst waiting. In addition, the family refusal rate to organ donation, when the donation request is made, is stubbornly fixed at around 40%. That is, nearly half of all potential donor families decline the option of organ donation when asked.

The purpose of this study is to better understand carer decisions relating to the organ donation request. It is recognised the vital role that critical care staff play in identifying and caring for potential organ donors therefore the sharing of experiences will help better inform future practice.

To achieve this, the study aims to recruit around ten critical care staff who have been involved in end of life decisions relating to the organ donation request of patients

within the critical care area. If you agree to take part in the study you will be required to consent to the following:

1. Participation in the study
2. For the researcher (me) to visit you at an agreed date and venue to participate in a taped interview about end of life decisions and the donation request (lasting no longer than one hour)

Why have I been invited?

Organ donation is only possible within the critical care areas and you work as a critical care nurse / doctor within the critical care units at Manchester Royal Infirmary. Your name has been provided by the Specialist Nurse – Organ Donation that works within the Trust because you have had recent experience of end of life care and the organ donation process. If you prefer not to participate, your name will not be held on any database or document.

What's involved? What will happen to me?

If you agree to take part in the study, the researcher will provide full details and go through the project with you. You will be asked a series of questions about your personal experiences of end of life decisions in relation to the organ donation request. If you decide to take part, you will be invited to participate in an interview which should take no longer than one hour. You can contact the researcher (me) to arrange a mutually convenient date, time and venue for the interview to take place. The interview can take place at a venue of your choosing, likely away from the critical care area to avoid disruption. The interview will be digitally recorded and later transcribed. All the data will be anonymised and all who are involved in the research are obliged to comply with the NHS Confidentiality Act and the Data Protection Act. The anonymised interview data will then be analysed by Greg Bleakley who is obliged to meet the requirements of the Data Protection Act at all times. Greg's contact details are at the end of this letter so please make contact if you have any fears, concerns or questions about the study.

Do I have to take part?

Taking part with this research study is entirely voluntary and it is up to you to decide. Greg Bleakley can meet with you separately to help you make an informed decision on whether or not to take part. You are free to withdraw from the study at any time, without giving a reason and it will not affect your relationship with the organ donation / critical care team in any way.

Expenses and payments?

There are no expenses or payments for participating in the study.

What are the possible disadvantages and risks of taking part?

Organ donation is an emotive subject and it is acknowledged that the interview may elicit emotional feelings of guilt, grief and anger. If the interview becomes upsetting, it will be terminated and the participant offered the opportunity to debrief. It may be necessary to sign post the participant to more expert help and support if this is identified. The participant can request that the interview is stopped, at any point, without having to provide a reason why.

What are the benefits of taking part?

Your participation will help better inform carer decisions relating to the organ donation request. In exploring the reasons why families / carers / relatives decline the option of organ donation, more life saving transplants may be possible. The study cannot promise that solutions can be found to reduce the family refusal rates to organ donation. However, in exploring critical care staff experiences, attitudes and behaviour it is hoped new knowledge and theory will be generated to better understand this phenomena.

What if there is a problem?

If you have any concerns or questions about any aspect of this study, you should ask the researcher – Greg Bleakley who will do his best to answer the questions (gregorybleakley@*****uk).

If you are unhappy and wish to make a formal complaint, this can be done by contacting Anish Kurien on the following:

Anish Kurien

Research and Innovation Manager

College of Health and Social Care

0161 *** ****

a.kurien@*****uk

Your data will be kept and managed in accordance with the NHS Confidentiality Act, the Caldicott principles and the Data Protection Act (1998). This means that your information will be stored as follows:

- All coded and anonymised data about you will be stored on a password protected computer accessed only by the researcher (Greg Bleakley)
- All hard paper data will be stored in a locked cabinet, within a locked office, accessed only by the researcher (Greg Bleakley)
- Electronic data will be stored on a password protected computer known only to the researcher (Greg Bleakley)
- Digitally recorded interviews may be sent to 'Out Sec' transcription services who are obliged to treat data according to the Data Protection act
- The data will be retained for five years and disposed of securely

What happens if I don't want to carry on with the study?

If you decide you no longer wish to participate in the study, the researcher will securely destroy all your identifiable data / tape recorded transcripts, but we will need to use the data collected up to your withdrawal.

What happens to the results of the research study?

- Your anonymised data will be used in the construction of a doctoral thesis with the University of Salford
- The findings from the study will help develop new knowledge on how best to engage with potential donor families

Who is organising or sponsoring the research?

The research is being sponsored by the University of Salford. This study has been reviewed by the University of Salford College Research Ethics Panel, approved by the NHS Research Ethics and the local Research and Development team within the Trust.

Researcher contact details:

Greg Bleakley

[Doctoral Student – University of Salford]

gregorybleakley@*****.uk

Tel:

Research supervisor details:

Dr Michelle Howarth

Senior Lecturer | Programme Leader MSc Nursing

Chair College Health & Social Care Ethics Panel for Taught Programmes

School of Nursing, Midwifery, Social Work & Social Sciences

Room MS 1.65, Mary Seacole Building, University of Salford, Salford, M5 4WT

t: +44 (0) 161

Email address | m.l.howar

@*****

Local contact support team:

Sarah Leo

Divisional Research Manager (Medicine & Community, CSS, Dental) Research & Innovation Division Central Manchester University Hospitals NHS Foundation Trust

Division of Medicine Offices, 2nd Floor Manchester Royal Infirmary Oxford Road Manchester M13 9WL

Tel: +44 (0)16 (please note this is a new telephone number)

Email: sarah.leo@

Appendix 10: Interview Schedule

Interview Schedule

Greg Bleakley

Professional Doctorate in Health and Social Care

Title of project: What influences critical care staff to consider engaging with relatives about organ donation following end of life decisions?

Question 1:

Tell me about your background and experience as a nurse

How many times have you cared for a potential organ donor?

Question 2:

Can you describe what happened when the decision was made to withdraw life sustaining treatment on a patient in critical care?

Probe questions (optional)

How did that make you feel?

Question 3:

Do you think the patient's age, medical condition and cause of death had any bearing on the decision to withdraw life sustaining treatment?

Question 4:

Is there any time when you believe (d) that organ donation should not be considered?

Probe

Do you think that a sudden or traumatic death with police and Coroner involvement makes the case more complex?

If yes – please explain.....

If they say 'no' –how will you develop this line of enquiry?

Question 5:

Can you tell about the skills you have used when identifying a potential organ donor?

Question 6:

Please describe how you feel about relatives / carers witnessing formal brain stem death testing?

Question 7:

Would you allow your organs to be donated for use in transplant operations?

If yes – please describe why

If no – please describe why??

Question 8:

Would you accept a lifesaving organ transplant for yourself or a member of your family?

Question 9:

Can you reflect upon a time when a patient was referred to the on call Specialist Nurse – Organ Donation as a potential donor?

Question 10:

Can you recall a time when a family was very upset with the situation and do you think their grief influenced the decision to donate or not?

Question 11:

How does the language we use when a patient is at the end of life influence decisions made by relatives / carers? Would you change the way in which you approached the relative?

Question 12:

Do you ever have any concerns or anxiety about the referral for organ donation or organ donation in general?

Appendix 11: Participant Consent Form

College of Health and Social Care,
University of Salford

Research Participant Consent Form

Title of Project: What influences critical care staff to engage with relatives about organ donation following end of life decisions?

Ethics Ref No:

Name of Researcher: Gregory Paul Bleakley

(Delete as appropriate)

- I confirm that I have read and understood the information sheet for the above study (Version (2) 29th May 2015) and what my contribution will be.

Yes	No
-----	----

- I have been given the opportunity to ask questions (face to face, via telephone and e-mail)

Yes	No
-----	----

- I agree to take part in the interview

Yes	No	NA
-----	----	----

- I agree to the interview being digitally recorded

Yes	No	NA
-----	----	----

- I understand that my participation is voluntary and that I can withdraw from the research at any time **without giving any reason**

Yes	No
-----	----

- I understand how the researcher will use my responses, who will see them and how the data will be stored.

Yes	No
-----	----

- **I agree to take part in the above study**

Yes	No
-----	----

Name of participant

Signature

Date

Name of researcher taking consent

Researcher's e-mail address

Appendix 12: Final letter following the Research Scholarship Award 2015-16

The Florence Nightingale Foundation

34 Grosvenor Gardens, London SW1W 0DH
Tel: 020 7730 3030 | Fax: 020 7730 6262 | Email: admin@florence-nightingale-foundation.org.uk



15 December 2016

Dear Greg

The Florence Nightingale Foundation/ NHS Professionals Ltd. Research Scholarship 2015-16

I really enjoyed reading the report of your scholarship and thank you for sending your final report in good time. I am content for you to send this to your sponsor Anne O'Brien at NHS Professionals and please do inform us that this has been done.

This is such an important and impactful study and organ donation is so topical. As you know the panel at your interview were shocked by the 40% family refusal statistic and were keen to see the results of your work. Delighted to see that you have managed most of the data collection and transcription now. I was so interested (but not surprised) that professional maturity and experience are key factors when dealing with sensitive issues and families in these cases. I look forward to seeing the final results of your work.

As you know, a requirement of your Scholarship is also now to go on and publish your work. There are two Journals whose Editors have offered to help Scholars if required. These are the *British Journal of Nursing*, and the *International Practice Development Journal*:

<http://www.britishjournalofnursing.com/> & <http://www.fons.org/library/journal.aspx>.

You are, of course, free to publish in other journals which are more relevant to your specific area of work. I appreciate your study is not finished but there has been much progress this year to write about. Please keep us informed of your progress on this. We and your sponsor should be acknowledged in any publication and we require a copy of the article for our files. The publication guidelines for scholars are attached.

Conference and poster presentations are also a valuable way of sharing and disseminating insights gained from your scholarship. The Foundation and your sponsor should be acknowledged in such presentations. Thank you for completing and submitting a comprehensive abstract, we will now make this available on our website.

www.florence-nightingale-foundation.org.uk  @FNightingaleF  The Florence Nightingale Foundation

Royal Patron: HRH Princess Alexandra, The Honourable Lady Ogilvy KG GCVO | Patron: Sir Robert Francis QC
President: The Baroness Watkins of Tavistock | Chairman: Mr Bryan Sanderson CBE | Chief Executive: Professor Elizabeth Robb OBE

A company limited by guarantee Registration No.518623 England | Charity Registration Nos. 229229 England & Wales, SC044341 Scotland

You are now entitled to call yourself a "Scholar of the Florence Nightingale Foundation" and we encourage you to make reference to this in your curriculum vitae. I also hope that you will attend the Florence Nightingale Commemoration Service held in Westminster Abbey on 17th May 2017. Tickets are free.

You will be invited to the biennial Presentation of Certificates in 2018, where you will receive a Florence Nightingale Foundation Scholar Badge and have the opportunity to meet sponsors and network with other Scholars. We will send out more information closer to this date. Please keep the Foundation updated on any changes to your contact details.

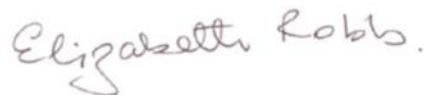
Unless you inform us otherwise we will keep your personal data on file in order that we can contact you. At some point in the future we may also invite you to participate in a scholarship evaluation.

You are now eligible to join the Alumni Association of the Foundation and we would strongly recommend that you do. The Alumni Association enables scholars to remain connected to the work of the Foundation and to engage with other scholars.

I hope that you will attend our Conference on Friday 3rd February 2017 and consider submitting an entry for the poster competition for the chance to win a range of prizes (flyer attached).

Finally, please do publicise our scholarships to your colleagues as we have more funds available for next year.

Yours sincerely

A handwritten signature in cursive script that reads "Elizabeth Robb." The signature is written in dark ink and is positioned to the left of the typed name.

Professor Elizabeth Robb OBE
Chief Executive

Appendix 13: Iterative process of data collection and analysis

