UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
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School of Nursing and Midwifery

'Shielding Behaviour'
Corneal Donation in the Hospice Setting

by

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ABSTRACT

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Human organ and tissue transplantation has proven to be a successful method for treating many medical conditions. However, the demand for organs and tissues is rising. One group of individuals who could be potential donors are those who die within the hospice setting. This thesis has examined whether corneal donation is a viable option to be discussed within the hospice setting. The views and feelings of stakeholders, including patients, bereaved family members, corneal recipients, hospice staff and donotransplant professionals were explored.

Seventeen face-to-face interviews and two focus groups were carried out with participants from the stakeholders' groups. Data were analysed using a grounded theory approach. A substantive theory of 'Shielding Behaviour' was developed, which explained stakeholders' views and feelings. The theory was developed from the integration of five categories: 'Shielding Behaviour', 'Knowing', 'Being', 'Gatekeeping' and 'Choosing'. 'Shielding Behaviour' was identified as the core category as it was the most pervasive theme expressed by participants.

The desire 'not to do harm' was essential for participants if corneal donation was to be discussed. Although there was an acknowledgement that individuals should have choices at the end of life, corneal donation did not conform to health care professionals' ideals of a 'good death'. Participants believed this could be as a direct consequence of insufficient knowledge of donotransplantation and inability to visualise the long term benefits for corneal recipients. Although participants agreed that individuals should be informed about donation, knowledge and attitudes held by health care professionals affected their ability to make the decision to inform patients and families.

Findings suggest that patients and their families do not object to being informed about, or discussing corneal donation in the hospice setting. However, to facilitate information exchange and discussion, health care professionals need education to explore their attitudes and increase their confidence in discussing this sensitive issue.

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Operational Definitions

Brain stem death: The phrase used to describe the establishment of death following irreversible destruction of the brain stem.

Cornea: The transparent, glasslike membrane of the eye, that lies directly over the pupil and iris. It acts as a refractive medium that deflects light rays, letting light into the lens and retina of the eye (Appendix 1).

Donation: The voluntary giving of body parts for transplantation or research purposes.

Donation operation: The surgical procedure for removing organs and tissue from a donor.

Donor card: A card that is signed and may be carried by a person to express their wish to donate organs and tissues for transplantation after they have died.

Donotransplantation: The process of organ and tissue donation and transplantation.

Hospice: A building where specialist palliative care is provided for individuals with life limiting illnesses.

Lack of objection: When after 'reasonable enquiry' there is no evidence of the deceased or their family members objecting to donotransplantation taking place.

NHS Organ Donor Register (ODR): Launched in 1994, it is a national database, based in Bristol at UK Transplant, where people may record their desire to be an organ or tissue donor. Individuals can register on the internet, via driving licences, in certain chemists etc.

Non heart-beating donor: These are donors whose deaths are determined by cessation of heart and respiratory function rather than loss of whole brain function.

Opt-in: This is the current system for organ donation in the UK, where individuals are asked to register their willingness to be a donor after their death.

Organs: Organs are defined as the heart, lungs, liver, kidneys, pancreas and intestines.

Palliative care: "Is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments" (World Health Organization 2002: p4).

Tissue: Any of the coherent collections of specialised cells such as corneas, heart valves, skin and bones.

Transplantation: The transfer of tissue or an organ from one body and implanting it in another.

UK Transplant (UKT): It is part of the NHS Blood and Transplant special health authority. UKT provides a 24 hour service for the matching, allocation and distribution of organs for transplantation. UKT manage the National Transplant Database which includes details of all donors and patients who are waiting for, or who have received a transplant. They maintain the National Organ Donor Register and have a remit to improve organ donation rates through funding initiatives in the wider NHS. UKT is a central point for information on transplant matters in the UK and Republic of Ireland and have a remit to raise public awareness of the importance of organ donation.

Introduction and Overview of the Thesis

Human organ and tissue transplantation has proven to be a successful method for treating many medical conditions. It not only provides extensions to life expectancy for individuals with irreversible organ failure, but also the opportunity of an improved quality of life for those with severe medical conditions. In the United Kingdom (UK) during 2004-2005, over 2,724 people received organs through transplantation, and a further 2,379 people received sight saving corneal transplants, also known as penetrating keratoplasty grafts (UK Transplant 2005a). These figures represent a 1% fall in the number of solid organs, a 3% fall in cadaveric donations, an 8% increase in living donations and a 1% improvement in corneal donation on the previous year. However, despite this overall increase in donation there has been a rise (6%) in people registered for a transplant and 460 people died waiting for a suitable organ during the year (UK Transplant 2005a). The demand for organs and tissues is rising worldwide due to extended health, improved surgical techniques and immunosuppressive agents. This trend is likely to continue, until as has been suggested, artificial devices and the use of donor organs from other species become a viable alternative (UK Transplant 2005a).

UK Transplant (2005b) reported that refusal rates for donation are a concern for UK transplantation programmes. UK refusal rates of 40%, rising to 70% among 'non-white' groups (UK Transplant 2005b) has led to a need to widening the scope of potential donors to clinical areas other than intensive or critical care. One group of individuals who could be potential donors are those who die within specialist palliative care units or hospices. Although patients who die of life limiting illnesses in these settings cannot be multi-organ donors, they can potentially, donate a variety of tissues and, rarely, their kidneys. In practice, corneas are the most common tissue to be donated. This is because the majority of palliative care patients have a cancer diagnosis and, unlike most other organs and tissues, a cancer diagnosis does not preclude corneal donation. Also, the donation process is relatively simple and can take place within the care setting, a mortuary or undertakers (Wells and Sque 2002). At the current time individuals who die of cancer are the third most common donors of corneas for transplantation purposes (UK Transplant 2003a).

With improvements in operative techniques and immunosuppressive agents, corneal transplantation has become an increasingly successful sight saving operation with a number of studies documenting survival rates of 90% - 100% of grafts functioning after one year (Price et al 1993; Price et al 1991; Bishop et al 1986). By five years, studies have shown ranges of between 50% - 80% are still functioning and many will continue for many more years after that (Price et al 1993; Price et al 1991; Bishop et al 1986). Bearing in mind the statistics from the Hospice Information Service (Help the Hospices 2005) indicate that approximately 30,000 deaths occur in hospices each year, this would suggest that hospices could potentially be a valuable source for corneal donation.

Whilst working as a hospice ward manager in the mid 1990s, I became aware that palliative care patients could donate certain tissue for transplantation after they die. This led me to implement informing patients and families that tissue donation was an option they could consider. Within a year the hospice had a lack of objection rate of just under 50% (Eye Bank Coordinator 1998, personal communication) for corneal donation. I was aware that although we were receiving positive responses, informing people about tissue donation was not the practice of other hospices. There was research available on donation in intensive care units but none within the hospice setting to use as evidence to support the practice. Therefore, as part of the requirements for the MSc in Advanced Clinical Practice (Palliative Care) I undertook a small study exploring the commitment of health care professionals to tissue donation in the hospice setting (Wells and Sque 2002). The results of the study identified that it was not just health care professionals who were influential to corneal donation taking place within the hospice setting and that other stakeholders' views needed to be explored.

This thesis charts the journey to explore corneal donation within the hospice setting. Five chapters are presented. As a grounded theory approach was used, the first two chapters provide the background literature that guided the initial stages of this research. Further literature is drawn in during data analysis to clarify and inform the findings. Chapter One, therefore addresses the history and current situation of tissue donotransplantation in the UK with a more focused examination of corneal donotransplantation. The historical influences, which may impact present day organ and tissue donation are examined and public and health care professionals' attitudes are critically evaluated with reference to the implications for corneal donation. Chapter Two examines the history and development of the modern hospice movement and specialist palliative care. This will include discussion about the medicalisation of palliative care and the 'good death' ideology. The chapter will conclude with a critique of the current literature pertaining to corneal donation in the hospice setting.

Chapter Three discusses the research methodology and methods used for this study. The aims of the study are presented along with a discussion about why a qualitative design was chosen. This is followed by a discussion of grounded theory methodology. Strategies implemented for sampling and recruitment are examined and how this was adapted during data collection to meet the aims of the study. The analysis process is made explicit through a step-by-step account. Ethical issues are then considered and how trustworthiness and authenticity of the study was ensured.

The findings of the study are presented in Chapter Four. In accordance with a grounded theory approach, the findings and discussion are presented together. Graphic representations of category development are presented to show the storyline of the phenomena being studied and the evolution of the theory.

The final chapter, Chapter Five, provides a critique and reflection upon the thesis. A reflection about the methodology and methods is discussed. The contribution this thesis makes in providing an understanding of the phenomena being studied and the implications for clinical knowledge and practice is presented. Discussion about the study recommendations for education, clinical practice and further research is provided. This is followed by the conclusion to the thesis.

Chapter One:
Background to the Study
Tissue Donation

1.1 Introduction

The first two chapters of this thesis will provide the background literature that guided the initial stages of this research and will also serve to put the study into context. A systematic approach was adopted for the literature review (Appendix 2).

This chapter addresses the pertinent issues surrounding tissue donotransplantation. It is divided into three sections. The first section provides an overview of the current situation regarding non heart-beating donation in the UK. This is followed by an examination of one specific form of tissue donotransplantation, that of corneal donation, which is the focus of this study. The history and development of corneal donotransplantation in the UK will be discussed. The second section will examine the historical influences, which appear to impact present day organ and tissue donation. This will include a discussion about the similarities between the acquisition of bodies for dissection in the past, and donotransplantation today. Also, how the apparent fascination with public autopsies may impact on individuals' willingness to donate their organs after death. In the third section, public and health care professionals' attitudes will be critically evaluated with reference to the implications for corneal donation. This section is presented in two parts. First surveys by questionnaires and secondly, qualitative exploratory work.

1.2 Tissue donotransplantation

1.2.1 Non heart-beating tissue donation

Veatch (2000) maintains that the donotransplantation community became so committed to procuring organs from people who died based on brain stem (neurological) criteria that they almost forgot the valuable source of organs and tissues from non heart-beating cadaveric donors. Whilst the reason for this may be due to strict donor criteria confining most solid organ donation to heart-beating patients maintained on ventilators, in the intensive care environment, individuals who die in other clinical areas can potentially donate a variety of tissues and, occasionally, their kidneys. Although tissue donation does not enjoy the same high public profile as organ donation (Odell et al 1998) it nevertheless holds many significant benefits for recipients. For example, the transplantation of new valves to patients with diseased or infected heart valves, can be life saving. Skin donation can be used to treat severe burns and corneal transplantation has the ability to improve or even restore sight for those with diseased corneas; enhancing the recipient's quality of life. Tissue donation is also subject to fewer contra-indications and restrictions than are associated with solid organ donation. Collection times are less urgent, varying from between 24 hours after death for corneas, to 48 hours for heart valves. Thus, according to UK Transplant (2005a), many patients who die in environments outside intensive care have the potential to be non heart-beating donors.

Donation from non heart-beating donors is not limited only to tissues. Although the majority of kidneys transplanted are from heart-beating or live donors, successful transplants have also been performed using kidneys from non heart-beating donors. Thus, with recent figures showing over 5,000 patients in the UK on the active kidney transplant waiting list (UK Transplant 2006), there has been renewed interest in the retrieval of kidneys from patients who have already suffered cardio-respiratory arrest. However, this type of kidney donation presents a unique set of problems associated with the increased risk of warm ischaemia (Kimber et al 2001). This is the amount of time the kidney spends at room temperature without an oxygen supply. To reduce the risk of damage to the kidney, removal needs to take place quickly and in an operating theatre (Kimber et al 2001; Lewis and Valerius 1999). Thus, although the donation of kidneys is theoretically possible from areas other than intensive care, in practice it is generally restricted to either the intensive care setting or the accident and emergency environment.

Despite the fact that many patients in a variety of settings could be non heart-beating cadaver donors, statistics suggest that only limited donation takes place from areas other than the intensive care settings (Wells and Sque 2002; Sque et al 2000; Gore et al 1992). Plausible reasons for this include the seemingly low commitment towards donation, of health care professionals working outside intensive care (Wells 2000), and their failure to either identify potential donors, or to introduce opportunities that might allow the donation process to take place (Gore et al 1992; Sque et al 2000). These reasons are supported by the results of a study investigating the knowledge and attitudes of health care professionals towards donotransplantation in different clinical settings (Sque et al 2000). Sque et al (2000) compared the knowledge, attitudes and behaviour of UK nurses, regarding donotransplantation, working in a variety of clinical settings. Postal questionnaires were sent to 2465 nurses working on general medical and surgical wards, accident and emergency departments, operating theatres, intensive care units and renal dialysis units. A 54% response rate (n=1333) was achieved. The results showed that renal dialysis nurses, followed by intensive care nurses, held the most positive views about the donotransplantation process. They also placed more importance on donation than nurses from other clinical settings and did not perceive that discussion about donation would increase families' distress. Conversely, nurses working in the operating theatre and on general wards were the least positive about donation, were more concerned about its interventionist and mutilating aspects, and believed that discussion about the subject with family members would increase their distress.

Sque et al (2000) concluded that whilst intensive care and renal dialysis nurses were both knowledgeable and supportive of the donation process, there was evidence of complacency regarding donation amongst accident and emergency nurses and negative attitudes amongst those working on general wards. This led the authors to propose that nurses who were involved with the donotransplantation process may have a more empathic response, and therefore be more positive about donation. Conversely, those who were not knowledgeable, and have no experience of the process, were likely to be more negative, possibly because they were not expected to consider facilitation of the donation process as part of their role. The results of this study are supported by those of Garde and Corbett (1994), Kiberd and Kiberd (1992) and Bridgare and Oermann (1991) who also found that nurses who had experience of donation, either personally or professionally, held more positive attitudes than those who had no experience.

1.2.2 Corneal donotransplantation

The cornea is the transparent outermost layer of the eye (Appendix 2). Although the cornea generally contains no blood vessels they do contain a complex network of nerve endings, which when damaged can be very painful. Light passes through the cornea and then through the lens to form an image on the retina at the back of the eye where the optic nerve is located. Sight is controlled by the optic nerve. Therefore, if the cornea is cloudy or scarred the optic nerve will not be able to activate the retina to produce the image in view. In corneal transplantation, or keratoplasty, the recipient's damaged cornea is replaced by the cornea from the eye of a human cadaver. The recipients' corneas are generally damaged by disease or trauma. Some of the diseases that may require a corneal transplant include Keratoconus (bulging outward of the cornea), Fuchs' dystrophy (malfunction of the inner layer of the cornea), Bullous Keratopathy (corneal oedema) and rheumatoid arthritis. A corneal transplant would also be considered if damage is caused by trauma such as chemical burns, mechanical trauma and infections including the herpes virus.

The first successful corneal transplantation in humans dates back to 1905, when Dr Eduard Zirm, an Austrian ophthalmologist, performed a human corneal transplant after obtaining tissue from an 11 year old donor (Doering 1996). This significant milestone was achieved only after many centuries of unsuccessful theories and experimentation (Moffatt et al 2005). It is believed that Zirm succeeded where others had failed due to advances in medicine such as anaesthesia and antiseptics (Moffatt et al 2005). It was not until the latter half of the 20th century that corneal transplantation was perfected with refinement of techniques and instruments, such as the circular trephine, which removes the damaged cornea, and the development of antibiotics, corticosteroids and suture materials.

The first eye bank, called the 'Eyebank for Sight Restoration' was founded in New York in 1944 by Richard Townley Paton. The main supply of corneas at that time was from executed prisoners (Moffatt et al 2005). After the development of the New York eye bank, networks of international eye banks grew rapidly making donated tissue more accessible and feasible. The world's first 'anatomical gift' programme was started in the USA, which allowed individuals to request the donation of their corneas for the good of others, after they died. Corneas were only able to be stored for a maximum of three days. Therefore, recipients were selected on the basis of urgency. It was not until the 1970s that preservation medium was developed, which allowed corneas to be stored for up to 30 days. This was an important step as it allowed time for microbiological screening and if required, tissue matching (Moffatt et al 2005).

In the UK corneal tissue is stored at the Corneal Transplant Service (CTS) eye banks in Bristol and Manchester. They receive eyes directly from donor hospitals or through the other UK eye banks (Norwich, East Grinstead and Moorfields). Guidelines about 'The Retrieval of Human Ocular Tissue Used in Transplantation and Research' were produced by the The Royal College of Ophthalmologists (2004). The guidelines provide assistance for medical and other NHS staff who are involved in eye donation. It sets out standards that must be achieved to allow corneal tissue to be used for transplantation or research. It includes information required to determine the suitability of a donor (Appendix 3), and eye removal, including the collection of a blood sample and restoring a donor's cosmetic appearance (Appendix 4).

Once a recipient has been identified, corneal transplant services will request the corneal tissue from the CTS eye banks. Surgical techniques for penetrating keratoplasty have many similarities to the original methods of Dr Zirm. The damaged cornea is removed with a cylindrical cutting tool called a trephine. The same trephine is used to cut the donated cornea so that the shape is identical. The donated cornea is then sewn into place. If the graft is a success, light will be able to focus onto the retina, optic signals will be channelled to the brain via the optic nerve and sight will be restored.

1.3 Historical influences

Moloney and Walker (2002) believe that the past, influences and constructs the present and that there is never an absolute reality that is free of a socio-historical context. In relation to organ and tissue donotransplantation, this concept is supported by Richardson (1996), who believes that the current problems in obtaining organs and tissue for transplantation are influenced by the history of body dissection. Richardson (2006; 2000) explored the history of death and dissection, in the UK context, and discussed the disturbing similarities between the acquisition of bodies for dissection in the past, and donotransplantation in the present day, including the demand for dead bodies being greater than the supply. She also suggested that the transplantation of organs and tissues could be perceived as a modern development of dissection, and surgery, as transplantation evolved from and built upon knowledge that was gained from centuries of exploring the human body.

Richardson's (2000) work explored from the Renaissance period when bodies of the dead were dissected to treat the living, by exploring and learning how the body worked and how illness and disease affected it. Dissection, like transplantation, relies on the availability of dead bodies to help the living. This necessitated surgeons to have a constant supply of bodies on which to research and practice. Prior to the Tudor period there was no legal stipulation about how bodies were obtained or treated (Richardson 2000). In 1540, Henry VIII bestowed upon the Companies of Barbers and Surgeons the annual gift of four hanged felons (Anno32 Henrici Octavi c.42 1540, cited by Richardson 2000). This caused insufficient and restrictive supplies of bodies leading to illegal and immoral methods of obtaining corpses, as supply was not meeting the demand. This is not dissimilar to the current situation of inadequate organs and tissue for transplantation and the reported illegal trading of organs on the black market (Cheney 2006; Scheper-Hughes and Wacquant 2002; Richardson 2000).

Renaissance society perceived dissection as judicial punishment and therefore a fate worse than death, leading Richardson (2000) to suggest that the loathing of dissection may have derived from fears that the process either damaged the soul or prevented resurrection, which is often given as the reason for refusing the request for donation of organs in today's society (Sanner 2001). This is particularly pertinent within this study, as many people believed that the eyes are 'the windows to the soul' and as such choose not to donate their corneas (Sanner 2001).

The illegal acquisition of bodies continued until 1828, when an anatomist, Dr Robert Knox, was prosecuted for illegally acquiring a dead body from two bodysnatchers called Burke and Hare (Richardson 2006; 2000; 1996). This was to change the future of obtaining bodies for dissection and within days became the subject of parliamentary interest. The shortage of bodies for dissection was investigated and strategies to increase the supply were established. The Anatomy Act (1832) was passed, which defined institutions such as hospitals and workhouses as having lawful possession of the poor dead. It allowed for any person who did not have family members or insufficient funds for a funeral to be used for dissection. This behaviour was also evident in the USA in the 1940's, when attempting to obtain corneas for transplantation. A New York eye surgeon was so determined to increase his supply of corneas for transplantation that he would drive 40 miles every time a prisoner was executed at Sing Sing Prison to remove the prisoner's corneas (Moffatt et al 2005). At that time prisoner donation was the only source of donor eye tissue in the USA. Richardson's (2000) work indicates that humans have been both fascinated and appalled at the thought of bodies being dissected for research, science or medicine for many centuries.

What Richardson (2000) proposed as a rationale for individual's beliefs and attitudes appears to continue today and have been highlighted in the past five years by two events in the UK. First, the public outcry at the discovery that the organs of over 5,000 children had been removed and stored by pathologists at Bristol Royal Infirmary and the Alder Hey site of the Royal Liverpool Children's Hospital without their families' consent (Department of Health (DH) 2001). There was concern that the events at Bristol and Alder Hey would lead to a reduction in the number of available organs and tissues donated for transplantation. Although, there was a reduction in the donation of organs and tissues directly after these events the figures are now showing a slow increase (UK Transplant 2005a). UK Transplant (2005a) has reported an increase in donors aged under six (five in the year 2000, 14 in 2001). They have proposed that the publicity surrounding organ retention may have contributed to the increase in young donors. Also the NHS Organ Donor Register (ODR), which records details of people who have pledged to donate their organs and tissue after death, has equally seen an increase in support. During February 2001 (immediately after the findings of the Royal Liverpool Children's Inquiry (DH 2001) were made public) there was an increase in the number of people who registered on the ODR. This increase was also thought to be a response to the publicity that surrounded the Inquiry and people's ability to differentiate between giving consent for organs to be used for transplantation and organs retained for research without consent (UK Transplant 2002).

Second, was the opening of the controversial exhibition 'Body World' and the subsequent televising of a public autopsy, carried out to a packed audience (Odone 2002). The originator, Professor Gunther von Hagens, believed that the 'Body World' exhibition and public autopsy served an educational purpose giving the public the opportunity to view the interior of the body. The public autopsy, performed by von Hagens in November 2002, sparked diverse media attention. A report in The Observer (November 24th, 2002, p8) discussed the response of two doctors who discussed the possible effects on organ donation. They said:

> *"It could prompt the audience to discard their reluctance to donate organs to medicine. More and more people are refusing to donate organs – because they assume that an autopsy leaves the body disfigured. Instead, as we witnessed on Wednesday night, after the autopsy, the body is sewn up again – even when it is stripped of those organs that, through transplant, can save other people's lives."*

Public autopsies were a regular occurrence up to the 18th century when the medical profession decided this should no longer happen. One possible conclusion that can be made is that the removal of autopsies from the public arena has confounded the attitudes and misconceptions that surround death and treatment of the body after death. Therefore, public autopsies by individuals like Professor von Hagen and television programmes, such as 'Silent Witness' and 'Crime Scene Investigated', which dramatise autopsies, could potentially impact on peoples' perceptions of what happens to bodies after death.

1.4 Attitudes towards donation

Negative attitudes towards organ and tissue donation are often cited as barriers to the donation. Attitude can be defined as an intention to act in a specific manner in relation to a specific issue (Sanner 2001), or a predisposition to behave in a particular way (Procter 2001). The availability of organs and tissue for transplantation is not only driven by public attitudes, but also health care professionals' personal and professional attitudes towards donotransplantation, and whether they believe it has a role within their practice.

Donor cards are considered a representation of an individual's positive attitudes regarding organ and tissue donation after their death (Manninen and Evans 1985). However in the UK the signing of a donor card is only one way of expressing this wish. People express their desire to donate their organs after death by an 'opt in' system, either by carrying a donor card or by registering their wish on the ODR. A report by New et al (1994) identified that 70% of the UK population were in favour of donation, but only 19% carried donor cards.

The shortfall in providing evidence to express the desire to donate organs and tissues led to the development of the ODR. Since its launch in 1994, 13,575,292 (23%) of the UK population have registered (UK Transplant 2006). These figures could indicate that awareness about organ donation alone is insufficient to turn general support regarding donation into a personal commitment by the signing of a donor card or registering to become a potential donor. Therefore, alternative approaches to the donor card or ODR need to be considered to indicate individuals' wishes to become organ donors.

1.4.1 Surveys by questionnaires

This ambivalence to confirm a decision regarding organ and tissue donation was examined by Parisi and Katz (1986). Through a verbal questionnaire to 110 adults, they measured people's attitudes toward various positive and negative aspects of organ donation (e.g. organ donation would allow me to help someone who is suffering and, organ donation leaves the body mutilated and disfigured) and assessed the relationship between these attitudes and willingness to sign a donor card. Participants were asked to rate 46 statements using a six point Likert scale ranging from strongly agree to strongly disagree. It was identified that those individuals who had both strong positive attitudes and weak negative attitudes were especially willing to sign a donor card. In comparison, strong negative attitudes toward organ donation with variability in positive attitudes, seemed to have relatively little influence on individuals' willingness to sign a donor card. One implication of Parisi and Katz's research is that individuals may be unwilling to sign a donor card if they have strong negative attitudes to one or more aspects of organ donation.

The sample group for this study was narrowly focused on two particular socio-economic groups and was not a random sample of the general population (87% from lower and middle management positions of several financial corporations and 13% drawn from students and personnel at one university), which may have biased the results. However, attitudinal questionnaires can be an effective method of gathering structured information from a large number of people (Kent and Owen 1995), although the disadvantages are that there is a loss of spontaneity and originality in the respondents' answers. The opportunity is missed for respondents to provide meaning and depth to their answers and when they are not expected to give reasons for their answers they may choose socially desirable responses (Perkins 1987).

Several studies have explored nurses' attitudes to donation (Kent 2004; Sque et al 2000; Kent and Owen 1995). Kent and Owen (1995) adapted the questionnaire devised by Parisi and Katz (1986) to measure nurses' attitudes towards cadaveric donation and in particular corneal donation. A convenience sample of 150 nurses from four clinical areas in three UK general hospitals, were invited to participate. One hundred and twelve, 74% of nurses, agreed to participate. The results showed that 79.5% of participants were willing to sign a donor card, whilst only 8.8% were unwilling to donate organs. Kent and Owen (1995) asked participants open-ended questions such as "Are there any organs you would not be willing to donate?". Twenty-five percent indicated that they would be unwilling to donate their corneas. Reasons given included, "the eyes reflect identity", "eyes are indicative of the individual person", "fear of disfigurement", "all other organs are internal-you can see the eyes" and "the belief that eyes are needed in the next life"(p490). The findings of Kent and Owen's study conflict with some of the findings of Parisi and Katz (1986). In particular the findings of Kent and Owen's (1995) study suggest that although some nurses had doubts about donation they were still willing to sign a donor card, which was not the case in Parisi and Katz (1986) study.

There is also evidence that suggests continued exposure to inconsistent messages about organ donation and transplantation is likely to foster ambivalence and unwillingness to make a firm commitment to posthumous donation (Parisi and Katz 1986; Horton and Horton 1990). Horton and Horton (1990) used a questionnaire to identify specific areas with regard to donotransplantation, which people had either misunderstood or had incorrect information. A random sample of 946 people responded to 21 true/false questions regarding factual knowledge about organ donation. The results identified that respondents were generally correct in answering questions regarding who is eligible to donate, the necessity of permission from the donor or next of kin, and that donation does not normally interfere with funeral arrangements. However, there were four questions which were only answered correctly by fewer than half of the respondents and Horton and Horton (1990) believe these may constitute serious barriers to people becoming potential donors. Sixty-one percent of respondents indicated that at least some major western religions do not support organ donation; 79.3% indicated that cessation of all pulmonary activity was necessary before organs can be removed; 55.8% indicated that they thought it not unethical for the same physician to have primary responsibility for donor and recipient. Horton and Horton (1990) suggest that the responses to the first three questions show a lack of awareness of the efforts made to protect the interest of the donor. Finally, 73.5% of the respondents indicated that for a donor card to be valid it had to be registered with the US Department of Health. Horton and Horton (1990) proposed that further research needed to address whether increasing knowledge regarding the four 'barrier' questions would lead to more positive attitudes towards organ donation, a greater willingness to sign a donor card, a greater willingness to donate a loved one's organs, and ultimately the potential to increase the supply of organs for transplantation.

What the previous studies allude to is that if people have the correct knowledge and information regarding organ donation, their attitudes and behaviour patterns could possibly be altered. A four-year study by Cosse and Weisenberger (2000) tracked the public's attitude towards donation and whether it changed following an advertising campaign about donation. The study consisted of four cross-sectional surveys conducted one year apart, with the first survey taking place prior to the advertising campaign. People were randomly selected (n=570) from a telephone directory to participate in a telephone survey. The results of the study indicate that there was no evidence of any change in attitude towards organ donation over the four years. However, what was significant was that the people who had both agreed or strongly agreed with the donation of their organs and who had signed a donor card showed a significant ($p<0.01$) increase from 39% in 1994, to 63% in 1997. This would indicate that although attitudes were not changed that commitment behaviour was influenced. What may have influenced this change in behaviour was that the advertising campaign emphasised "share your life, share your decision". In other words it is not sufficient to think positively towards donation, one must act positively. The advertising campaign influenced only those people who agreed with donation but until the publicity had not signed a donor card.

Knowledge and awareness does not only influence potential donors and their families' attitudes to donation, it is also the case for many health care professionals. As part of the first phase of a three year study exploring the psychosocial factors that influence nurses' willingness to discuss donation, Kent (2002) explored knowledge deficits. A cross-sectional sample of 776 randomly selected registered nurses, were accessed from five district general hospitals (within two NHS Trusts) with a response rate of 326 (42%). Randomised sampling occurred by obtaining the names and grades of all nurses from each hospital. Each nurse was allocated a number with half being randomly selected by a computer for the study. The author justifies her sample areas as she states that district general hospitals are where the majority of asystolic and brain stem deaths occur. It is regrettable that nurses from hospices were omitted from the sample group, when you consider the number of individuals who die in this area who are potential donors.

Data were collected using two self administered questionnaires. The Organ Donation Attitude Scale devised by Parisi and Katz (1986) and modified by Kent (Kent and Owen 1995) and the Organ Donation Attitude and Knowledge Scale, based on a tool developed by Gaber et al (1990). Both of these questionnaires appeared to have an acceptable level of internal reliability, although Kent (2002) argues that they required further testing to identify redundancy in the first questionnaire and to improve reliability scores in the second. The results indicated that 63% of respondents reported an assessment of potential donors rarely or never happened. In Trust 1, 43% of respondents felt confident to discuss donation, compared to 50% in Trust 2. Reasons for being able to discuss donation included knowledge, experience and existence of a close, caring professional relationship with family members. Knowledge deficits appeared to inhibit donation discussions particularly when there were fears about the donation process. Kent (2002) proposed that these fears may cause nurses to be more likely to avoid discussing donation. A recommendation arising from this study was that there is a need for further education, greater preparation for health care professionals through experiential learning, role modelling, and the provision of support mechanisms.

1.4.2 Qualitative studies

Sanner (2001) examined the reasons why people were either willing or unwilling to commit to become an organ donor. Sixty-nine participants from varying socio-demographic backgrounds took part in face-to-face interviews, which were analysed using a hermeneutic approach. This approach allowed the author to explore each participant's views and feelings and how these influenced their attitudes.

The results of the interviews showed one of the attitude patterns formed was that those participants who were willing to donate after their deaths or receive organs had a very clear image of their bodies as an object or machine and of 'possessing' a body rather than 'being' a body. This group also indicated a weak death anxiety characteristic, which was considered to be those who did not fear their death and its implications. In comparison the group that was neither willing to give or receive organs had very strong death anxiety attitude patterns and had many fears and concerns about their deaths. They viewed transplantation as breaching the boundaries of nature, with one participant stating that 'Transplantation is a manipulation of life itself' (p1495). There was also a strong religious element to participants' decisions, which included having beliefs in reincarnation and direct resurrection of the earthly body, whereby every molecule of the body was needed in the next life. Sanner (2001) pointed out that this view did not correspond with any known religion, but instead was "a homemade mixture of elements including both wishful thinking and quasi-scientific ideas" (p1495).

There was also a focus on the changes of identity. Participants indicated that eyes, skin, and the heart would be more difficult to donate or receive than a kidney or liver, as they were more personal, because they could be seen or sensed. These outcomes confirm the results of an earlier study by Skowronski (1997) which identified that donation of particular organs affect people's decision making. Participants were asked to put in order the organs they would most like to donate. The results in decreasing order of importance were: kidney, pancreas, heart, liver, lungs, skin, corneas, bones, all organs, brain tissue, and sex organs. However, the study did not illuminate participants' rationale for listing organs and tissues in that order and of particular interest why bones, all organs, brain tissue and sex organs were less popular than corneas. The findings of Sanner (2001) and Skowronski (1997) support the results of Parisi and Katz (1986) and Kent and Owen (1995) when considering attitude patterns towards commitment to donate organs or tissue after death.

Following on from earlier work (Kent 2002), Kent (2004) explored if there were reasons, other than knowledge, to explain the reticence of nurses to discuss organ and tissue donation. A phenomenological approach was adopted to make explicit the behaviours and actions of participants. The study took place in two geographical regions of the UK, one rural and the other industrial. Thirty registered nurses were purposively selected to participate in semi-structured interviews. All participants were registered nurses who were caring for adult patients in acute care settings. The interviews focused on four key areas: previous experiences of the donation operation, knowledge about the donation process, the donation process itself, i.e. focusing on the meaning that this had for the nurse, and views on increasing donor awareness about opportunities to donate and how this could be achieved. The findings put forward the concept of protective behaviour. Kent (2004) found that nurses' 'protective behaviour' appeared to influence their confidence levels, attitudes and ability to become involved in donor identification and discussion. Kent (2004) proposed that further research was required to examine why this protective behaviour was present.

1.5 Summary

The literature identifies that between 70-73% of the public would be willing to donate their organs and tissue after their death. However, in reality this figure does not reflect the current donation rates compared to the potential availability of organs and tissues. Possible explanations for this shortfall have been discussed, particularly the impact of history on traditional behaviour and the different attitudes and beliefs of both the public and health care professionals that strongly influence an individual's willingness and commitment to donate. Of particular importance for this study is the symbolic meaning of eyes to individuals and how this affects corneal donation rates.

This chapter has also shown that there are several surveys and questionnaires that have examined the attitudes of the public and health professional towards organ and tissue donation. None of these studies have considered whether there are changes in people's attitudes when they become aware they are living with a life limiting illness and whether this affects their decision making. Also, there is limited qualitative evidence to examine alongside the survey results when considering strategies to increase awareness and acceptance of organ and tissue donation. The next chapter will examine specialist palliative care and the current literature about tissue donation in hospices.

Chapter Two:
Background to the Study
Specialist Palliative Care and Corneal Donation

2.1 Introduction

The literature in this chapter is presented in two sections. The first section will provide an underpinning of specialist palliative care. This will address the history and development of the modern hospice movement and specialist palliative care. A definition of palliative care will be examined and how this has changed with the evolution of the speciality. Due to the extensive amount of published literature on hospices and palliative care, I have only selected literature that is relevant to this study. This will include discussion on the debate surrounding the medicalisation of death, the 'good death' ideology and strategies to facilitate end of life care. The second section will discuss the current literature pertaining to organ and tissue donation in the hospice setting. The literature is limited to five studies, three of which have been published. All these studies are UK based and therefore, were used to guide the development of this study.

2.2 Specialist palliative care philosophy and practice

2.2.1 Evolution of the 'modern' hospice movement

The Irish Sisters of Charity were the first to use the word hospice in the UK. They established Our Lady's Hospice in Dublin in the late 19th century and later founded St Joseph's Hospice in Hackney (Saunders 2000). The term hospice was first applied to the specialised care provided to the dying patient in 1967, by Dame Cicely Saunders who founded what is considered the 'symbolic reference' of the first 'modern' hospice, called St Christopher's Hospice in Sydenham. Authors have discussed how we should be cautious of making comparisons between the 'modern' hospice movement and those that were in existence before (Clark and Seymour 1999; Storey 1996; Saunders 1993). However, Clark and Seymour (1999) discuss how "in retaining the name, modern hospices have sought self-consciously to rekindle the tradition of devotion, calling and the ethics of service which was enshrined in the religious foundations of their predecessors" (p66). It is believed that the term 'hospice' was chosen to capture the ideology of a medieval way station for travellers and to represent the spiritual underpinning of the hospice movement (James and Field 1992). This is reinforced by the large number of hospices that were named after saints. Saunders (2000), Clark and Seymour (1999), James and Field (1992) and Saunders et al (1981) discussed factors that were considered key to the development of hospices and the palliative care philosophy. These included a combination of a search for alternative ways of dying, changing demographic and epidemiological trends whereby there was a shift in causes of death from infectious diseases to chronic life threatening diseases (Clark 2006), the institutionalisation of death, public attitudes and expectations of health care and changes in medicine where the disease was the main concern rather than considering the person as a whole. This is supported by White (1999), who discussed how palliative care developed partly in response to the negative impact of over-medicalisation upon patients dying within depersonalised and technological healthcare settings. Gannon (2001) suggests that by focusing on the patient rather than the disease technical aspects of care are minimised and only pursued if considered in the best interest of the patient.

Cicely Saunders' initial impetus was to provide symptom control, with the priority on pain control. This, along with the principle of St Christopher's having a strong education and research agenda, quickly led to the introduction of innovative new approaches to pain control and an acceptance of hospice care by the medical profession (Seale 1998). The main driving force for this change was Saunders concept of 'total pain', taking a holistic approach to pain control which not only considered physical issues, but also the emotional, social and spiritual aspects of suffering (Clark et al 2005; Saunders 2000; Seale 1998).

The success of St Christopher's led to a rapid growth in specialist palliative care services. By 1991, 430 palliative care services, including inpatient units, day care and community services had been established (James and Field 1992). This number has continued to increase with the 2005 Hospice Directory indicating that there are 253 inpatient units (33 of that number being for children), 358 community palliative care services, 104 hospice-at-home services, 263 day hospices/centres and 293 hospital support teams (Help the Hospices 2005). Of the 253 inpatient units 189 remain independent sector services and are dependent on the support of the local community.

Each year the National Council for Palliative Care (NCPC) complete a national survey of patient activity for specialist palliative care in England, Wales and Northern Ireland. For the 2005-2006 survey (NCPC 2006), 187 (87%) inpatient units responded. The units varied from 2 to 61 beds providing a total of 2774 beds. The patients were admitted from various locations: The majority (69%) being admitted from their home and 28% being hospital transfers. The results of the survey show that 52.3% of all admissions to inpatient units result in death, with the remainder of patients being discharged to their homes, care homes or other hospitals. The NCPC estimate that for 2005-2006 there were 28,000 deaths in palliative care inpatient units in England, Wales and Northern Ireland. This is a 1000 death increase on 2004-2005.

The term 'palliative medicine' was not used until the 1980s. Prior to that time hospices provided 'terminal care' or 'care of the dying'. Doyle (2003) describes how these terms although meaningful to health care professionals were distressing to patients and families. It is believed that three factors were fundamental to palliative medicine gaining authority and credibility in the 1980's (Doyle 2004). The Association for Palliative Medicine (APM) was formed to support medical practitioners, the scientific journal '*Palliative Medicine*' was established and palliative medicine became recognised as a specialty in the UK.

The definition of palliative care has changed several times since palliative medicine became a specialty in 1987. Doyle (2003) suggests we should be cautious and avoid further changes as he believes the current definition satisfactorily defines the aims and purpose of the specialty. The definition of palliative care, which is widely adopted in the UK, was developed by the WHO (2002).

> *"Is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments" (World Health Organization 2002: p4).*

The WHO definition clearly states that palliative care is an approach that improves the quality of life of patients living with a life limiting illness and their families. Early hospice care focused on the care of patients with a cancer diagnosis and was explicit in early definitions. This led to criticism that hospices were only accessible by the 'privileged minority' of individuals with cancer (Doyle 1993). The WHO (2002) definition has made it explicit that palliative care is no longer an exclusive service for patients with a cancer diagnosis.

Although hospices frequently provided care to patients with neurological diseases such as Motor Neurone Disease and Multiple Sclerosis, it was not until 1998 that the National Council for Hospice and Specialist Palliative Care Services highlighted the need to extend palliative care services to all patients with life limiting illnesses regardless of diagnosis (Addington-Hall 1998). Addington-Hall et al (1998), using data from a Regional Study of Care for the Dying (Addington–Hall and McCarthy 1995) carried out a secondary analysis of data to investigate what proportion of individuals who die with a non-cancer diagnosis would benefit from specialist palliative care services. Data was collected from relatives of 3,696 patients who had died within 20 English health districts in the last quarter of 1990. The results suggest that 16.8% of individuals with diseases other than cancer and their families would benefit from specialist palliative care services. In particular the management of symptoms, in encouraging autonomy and communication relating to issues related to death and dying. The need to extend specialist palliative care to patients with a non-cancer diagnosis is supported by Addington-Hall and McCarthy (1995) and Skilbeck and Payne (2005) who suggest that this patient group will generally suffer complex symptoms for longer due to the chronic nature of their disease. The 2005-2006 survey of specialist palliative care activity (NCPC 2006), shows that 10.8% of referrals to specialist palliative care services had a non-cancer diagnosis. The survey also showed that 6.1% of admissions to hospice in-patient units had a non-cancer diagnosis. Although specialist palliative care services acknowledge the need to extend their services to patients with a non-cancer diagnosis, there is concern that patients with non-cancer diseases such as heart failure, renal failure and respiratory disease have palliative care needs which are not necessarily transferable from those of patients with cancer (Field and Addington-Hall 1999). This requires health care professionals to recognise the differences in needs for those individuals with a non-cancer diagnosis and also the skills that will be required to care for them.

Not only does the WHO (2002) definition suggest extending specialist palliative care services to those with a non-cancer diagnosis, it also states that many aspects of palliative care may be beneficial earlier in the course of people's illness in conjunction with other treatments. To introduce specialist palliative care services earlier raises the issue of resource implications to provide this service. Field and Addington-Hall (1999) have discussed how specialist palliative care services are already stretched caring for those individuals living with cancer. Over 50% of the funding for hospice services is through the voluntary services with the NHS contributing a proportion of the costs (Hockley 1997). Hospice services are still heavily reliant on the fundraising and support of the local community. There is no evidence to suggest that this will increase in the future. Addington-Hall and Karlsen (2005) look at the current debates through a national survey of voluntary hospice services. The survey focused on staff and volunteers' views of the purpose of hospices and also their thoughts on the current debates. Nineteen hospices were randomly selected. A questionnaire was completed by 215 volunteers, 43 doctors, 129 nurses, 53 nursing auxillaries and 64 other staff. The results of the study show that although hospice volunteers agreed with patients with a non-cancer diagnosis having access to hospice services they were less positive than hospice staff. The participants were also asked if they agreed with the statement 'providing terminal care is no longer the most important part of the hospice's role'; 51% of nurses and 44% of doctors agreed with this statement, compared to 22% of the volunteers. Although hospice volunteers cannot represent the views of the general public what the findings of this survey show is that hospice volunteers have different attitudes to the changes in hospice care.

2.2.2 Medicalisation of palliative care

James and Field (1992) discussed how palliative care developed because of the perceived over medicalisation of dying in health care and the need to develop non-invasive strategies to manage symptom control. The recognition of palliative medicine becoming a specialty in 1987 has led to concern that the 'medical model' has become the dominant force within palliative care and whether the shared view of palliative care remains (Clark 2002; Ahmedzai 1994; Field 1994; McNamara et al 1994; James and Field 1992). James and Field (1992) discuss how 'routinisation' and 'medicalisation' crept into specialist palliative care and led to opposition to the inclusion of invasive investigations and treatment. Field (1994) furthered his debate by suggesting concerns that there was the potential to shift away from end of life care and the concept of a 'good death' by the inappropriate use of medical technology. In a response to Field's (1994) paper, Ahmedzai (1994) responded by accusing Field of misunderstanding what hospices do, interpreting the paper (Field 1994) as saying that the development of palliative medicine as a specialty could lead to the inappropriate use of interventions and technology.

Other authors have discussed how there has been a move to a more interventionist approach to palliative care and provided justification for this change (Meldrum 2005; Seymour et al 2005; Seymour 2005; Clark and Seymour 1999; Ahmedzai 1994, 1993; Johnson et al 1990). Ahmedzai (1993) debated this shift and although cautions that an interventionist approach could lead to a return to disease centered approach to palliative care, he also questions that active approaches to symptom control can improve patients' quality of life. Examples of this are the administration of blood transfusions and the treatment of hypercalcaemia. This was also discussed by Seymour (2005) who believes that the idea of the early 'modern' hospice movement being opposed to technology and medicine is a myth. She proposes that the early hospice founders were innovative and supportive of medical interventions to optimise symptom control approaches. This is clearly evident in the collaborative approach between palliative care and Napp Pharmaceuticals in the development of MST Continus, a sustained release morphine preparation for pain control (Seymour et al 2005).

McNamara et al (1994) investigated whether the increasing institutionalization of hospice care and encroachment of medicine compromised palliative cares founding principles. This was the first part of a larger study, which will be examined in the next section on a good death. A qualitative design using an ethnographic approach was used throughout the study. Twenty-two Australian nurses were interviewed and participant observation was incorporated to complement the interview data. They identified that nurses believed the encroachment of mainstream medicine and medical technology were factors that competed with the ideal of a 'good death' in hospices. These were only the views of nurses and did not include the accounts and views of other stakeholders including patients and families.

The views of patients and nurses were later considered by Meystre et al (1997) who challenged their views about the use of technology and interventions within the hospice setting. An interview survey design was implemented to investigate and capture the attitudes of terminally ill patients (n=23), and nurses (n=18) towards investigations and invasive procedures. Patients and nurses were asked about 14 procedures ranging from temperature taking to having a surgical procedure. The patient's questions were prefaced by: "If we thought it would help us improve your care would you want…?." Whereas, the nurses were asked how appropriate it was to carry out the 14 investigations. The results showed that patients were consistently more likely to accept investigations and invasive procedures than the nurses. What this study did not take into account was the importance of information and communication provided to patients by health care professionals, regarding the interventions, these being important factors in the decision making process for patients and their families. However, what this study highlights is that care must be taken to ensure that the attitudes of staff do not deny patients' choices in approaches to their clinical management.

2.2.3 The concept of a 'good death'

The term 'good death' has been informed by several historical, anthropological and sociological definitions (McNamara et al 1995). Aries (1981) in the book *'The Hour of Our Death'* linked the term to an "acceptable" way of dying. Aries (1991) described a good death as a fixed moment in time, whereas others propose that it is a series of events that occur at the end of life. Prior to the development of the 'modern' hospice movement some researchers considered a good death as a series of events not confined to a set period of time. The most well known of these is the work of Glaser and Strauss (1965) who studied the experience and behaviour of dying patients and developed the still commonly cited concepts of acceptance and awareness of dying. Although widely criticised for being too prescriptive, the work of Kubler-Ross (1969) is also considered influential in our understanding of a good death (McNamara et al 1994). Particularly, the five stages of dying and acceptance of dying.

The ideal of a 'good death' has become synonymous with the founding principles of the 'modern' hospice movement. It has been advocated as the central practical goal and has had great emphasis through educational influences and research studies. This has led to significant reference to the concept in the palliative care literature (Masson 2002; Seymour et al 2002; Bradbury 2000; Clark and Seymour 1999; Payne et al 1996; Low and Payne 1996; McNamara et al 1995; McNamara et al 1994; Kellehear 1990; Glaser and Strauss 1965). The concept of a 'good death' is not straightforward and has therefore been difficult to define and agree. Bradbury (2000) attempted to categorise the concept of a 'good death' into three types; a good medicalised death when death is anticipated and pain-free, a sacred good death whereby those with faith place an emphasis on how the deceased had lived and the manner of their death, and lastly a natural death which Bradbury (2000) separates into two types. The first type of natural death is described as individuals taking control of their death by being actively involved in decisions. Second, the death is deemed natural if it is sudden and unexpected. It is unclear if Bradbury (2000) had considered in categorisation of a good death that death cannot always be well managed and controlled, even in a hospice environment, and that what is considered 'good' to one individual may not be the same for another.

It is also important to consider how health care professionals perceive a good death. McNamara et al (1994, 1995) explored the relationship between perceptions of stress in palliative care nursing and the ideas of a good death. Twenty-two Australian palliative care nurses were interviewed and observed during meetings, handovers and in clinical practice. The findings of this study suggest that stressors which affected nurses were ones that threaten their shared system of values and were central to the goals of a good death. This study showed that nurses shared the hospice philosophy of promoting a good death. A death was considered 'good' if there was an awareness, acceptance and preparation for death by all those involved. However, when societal attitudes and beliefs threatened these value systems, stressors occurred, particularly if they conflicted with the nurses' ideas of a 'good death' within the hospice environment. Within this study death was conceptualised as a series of social events which not only involved the patient but was influenced by those around them; including family members and health care professionals. This supported earlier findings by Glaser and Strauss (1965) and Kubler-Ross (1969). McNamara et al (1994) conclude by saying that the ideology of a 'good death' helps hospices by supporting their philosophies and goals and by establishing "a degree of stability within the growing institutions of hospice care" (p1504). They caution that this approach by adopting the ideology of a good death, could potentially lead to rigidity of definitions and limit the ability to be spontaneous in provision of care, behaviour which could challenge the developing hospice movement.

Payne et al (1996) furthered the debate by comparing the concepts of a 'good death' used by patients and staff in a hospice, as a response to the suggestion that health care professionals, who work in hospices, have developed an idealised concept of dying. This was a qualitative study using semi structured interviews to collect data from 18 patients and 20 health care professionals including nurses, physiotherapists, occupational therapists, social workers and doctors. The data were analysed using content analysis. The patients were asked an open-ended question: Have you an idea of what would make a good death? Whilst the health care professionals were asked their perceptions of a good and bad death.

The findings of this study indicated that there were differences in the views of patients and health care professionals. Patients rated dying in one's sleep, quietness, dying suddenly, with dignity and being pain free as important elements to a good death. Whereas the health care professionals rated being pain free as being the most important factor, with family acceptance, being peaceful, not being anxious and the presence of a 'loved one' being important. Health care professionals also linked a bad death to uncontrolled symptoms and the risk of haemorrhage. The responses of the health care professionals highlight their importance of symptom control to a good death. Payne et al (1996) believe this could be a reflection of the medical model that is adopted by many hospices. This study was based in one hospice and only patients who used the words 'death' or 'dying' were invited to participate. By only recruiting patients who used the words 'death' or 'dying' could have led to biased findings. Also, by only recruiting participants from one hospice could raise issues of transferability of the findings to other settings.

In an effort to deal with this concern and possible criticism Low and Payne (1996) used the findings of the Payne et al (1996) study to develop a questionnaire. The aim of the questionnaire was to investigate health care professionals' perception of both a good and a bad death and their perception of patients' awareness context. Categories which were mentioned by at least two of the first 20 interviewees, from Payne et al's (1996) study, were included in the questionnaire. A total of 19 categories described awareness context, 12 categories described good death and 12 bad death. Statements were used to construct the questionnaire and were rated on a five point Likert scale. Seventy questionnaires were sent to hospice nurses and social workers with a 74% response rate. The findings of this study support Payne et al's (1996) previous work, showing that health care professionals perceived a good death as both controlling the patient's physical pain and suffering and also preparing the patient and their family psychologically for the death. Whilst, a bad death was considered as being unable to control the patient's pain or insufficiently preparing them for death. Again the sample for this study only consisted of hospice health care professionals from one county in the South of England and was not a representation of a larger geographical area. Regardless of this the findings did confirm many of the results of McNamara et al's (1994) study which suggested that hospice nurses have an idealistic view of what constitutes a good death and when these are not achieved it could lead to stress within the team.

Masson (2002) moved beyond what he describes as 'the compilation of idealised ingredients' of a 'good death' to investigate how these 'ingredients' get mixed in the real world context. Twenty participants were recruited to take part in the study; 10 hospice day care patients and 10 bereaved family members of patients who had died at the same hospice. Participants were requested to provide two stories about the death of people they knew. One about a death they considered to be good and one where they perceived it to be not good. The qualitative data that were collected was analysed using a content analysis. The findings indicated that patients expressed fewer issues than relatives that go towards having a 'good death'. Both patients and relatives expressed physical comfort, being at peace, normality, patient and family control and preparation for death being core features of a good death. Whereas, relatives, and not patients, also expressed awareness and shared reality, legacy of living and dying, communication and information and environment of care as core features. Masson suggests that patients were more focused on what constitutes a 'good death' than family members. Masson (2002) hypothesised that this could be representative of a change in patients' priorities and expectations when they reach the end of life. Masson (2002) suggests that a dynamic process emerged from the results whereby participants strove to achieve as near as possible their perceptions of a good death. Due to the complexities and variations in beliefs of the participants, Masson (2002) proposes that the term 'good death' should be changed to 'good enough death' to reflect the difficulties and limitations that are often features of end of life care. This would enable people to strive together to achieve as close as possible a death which meets the wishes of the dying patient. McNamara et al (1995) proposed that hospice nurses use the 'good death' concept as a coping strategy as it allows the validation of their value system and places death in an idealised context. By changing the term to 'good enough death' this could threaten nurses' value system as suggested by McNamara et al (1995) and lead to stress and anxiety for nurses.

2.2.4 Delivery of a 'good death' to all

Over the past five years there has been an increased interest and focus in the UK on good end of life care. Several inter-related factors have stimulated a political push to improve end of life care. Among these are the continued development and sustainability of palliative care services, media interest and attention to end of life issues and public interest and support for equality and its importance within the health care agenda.

A recent ICM Research (2006) study explored the UK public's (n=1027) views on how to have a good death. The survey took place on the 16th July 2005. The results indicated that 47% of individuals wish to die at home with only 10% wishing to die in hospital and 3% in a hospice. These findings support previous surveys relating to preferred place of care at the end of life (NCHSPCS 2004). Further results showed that 78% of participants wished to be informed that they were dying with 80% considering it as important for health care professionals to consider their feelings as well as their medical needs. When individuals were asked to list eight factors in order of importance at the end of life, being with the ones you love was rated the highest, closely followed by being pain free and maintaining dignity. The least important were discussions relating to religious and spiritual needs and discussion regarding feelings. These findings support the Government's stance on improving the delivery of end of life care in all health care settings (DH 2006; NICE 2004; DH 2003).

Government policy on palliative care has been driven by the realisation that NHS patients and their families should receive palliative care wherever they are and tailored to their needs (NCHSPCS 2004). The publication of the NHS Cancer Plan (DH 2000) was an important point in the development of palliative care with a commitment that "the care of dying patients must improve to the level of the best" and that "all patients should have access to the specialist palliative care advice and services that they need". With this commitment came money to the sum of £50 million with the expectation of reducing inequality of access to services. This was insufficient financial investment with the current Government White Paper (DH 2006) acknowledging the need to invest further into palliative care provision.

The NHS Cancer Plan (DH 2000) also suggested the developing of NICE guidance on supportive and palliative care. NICE published the guidance in 2004 with a mixed response, particularly surrounding concern that the title of the guidance focuses on cancer and does not account for the move to provide access to palliative care services for all those with life limiting illnesses who require specialist palliative care (Addington-Hall and Higginson 2001; Field and Addington-Hall 1999; Addington-Hall et al 1998; Addington-Hall 1998). Regardless of the title, it is clear that much of the content is transferable to other patient groups. It became apparent very early after publication that for all the recommendations to be met, further investment was required. This was supported by the government paper 'Building on the Best, Choice, Responsiveness and Equity' (DH 2003) which was committed to providing £12 million over three years to implement three initiatives throughout the UK. These were the Liverpool Care Pathway (LCP) (Ellershaw and Wilkinson 2003), the Gold Standards Framework (GSF) (Thomas 2003) and the Preferred Place of Care (PPC) (Pemberton et al 2003).

The LCP is a clinical tool that is used to facilitate care for patients in the last days of life. The aim was to transfer the best of hospice care into other care settings by prompting good communication, anticipatory planning and care after death (Ellershaw and Wilkinson 2003). The GSF is used within the primary care sector when the decision has been made that a patient's prognosis is considered less than six months (Thomas 2003). It helps the multi disciplinary team plan and coordinate end of life care. Finally, the PPC is an example of an advanced care plan and is a document that patients retain and use where necessary (Pemberton et al 2003). Some progress has been made with current figures showing that as of December 2005; 28% of primary care GP practices, 60% of acute Trusts, 47% of hospices, 11% of community hospitals and 0.75% of care homes were using one or more end of life tools (DH 2006).

2.3 Corneal donation as part of end of life care

Discussion within this chapter has included the debate around what constitutes a good death, with a key feature being to respect the views and wishes of the patient (Woodward 1998). Health care professionals within hospices pride themselves on their ability to communicate with families and to help them in their bereavement (Feuer1998). Although this is the case there appears to be little consideration to corneal donation being offered as an option for patients and families at the end of life. Spivey (1998) supports this lack of consideration in a study on tissue donation in hospices. In response to a questionnaire from 55% (n=83) of the hospices in England, it was found that 33 units believed that donation was appropriate, 17 believed it was inappropriate and 32 did not know or gave reasons for not participating. Of the 33 units who believed that donation was appropriate only two reported that they routinely discussed donation with patients and families and the remainder only participated when the patient or family initiated the enquiry.

The hospital intensive care unit is generally considered the place where the request for donation of organs and tissues takes place. This assumption is supported by a lack of literature published on organ and tissue donation in areas other than intensive care units. Only four studies have explored organ and tissue donation in hospices (Peters and Sutcliffe 1992; Wells and Sque 2002; Carey and Forbes 2003; Hughes 2005). Peters and Sutcliffe (1992) presented an account of 12 asystole kidney donors who died at St Christopher's Hospice, London between January 1990 and October 1991. This study reviewed the patients' medical records. The positive effects for patients and families were discussed and issues raised for staff explored. This was a reflective piece of work. It was the earliest published work on organ donation in the hospice setting and stimulated thought and discussion amongst health care professionals. However, the criteria for kidney donation have changed since the date of this paper and therefore, the reality of kidney donation from patients who have died in hospices has become more complex and rarely happens.

Wells and Sque (2002) explored why the commitment to tissue donation in hospices was low. A sample of eight nurses and doctors employed within two hospices were invited to participate in semi-structured interviews to explore their views, feelings and experiences of tissue donation within the hospice setting. The findings showed that health care professionals in hospices are in a unique position in that their patients are often aware that they are dying, as are the patients' families. This awareness makes the subject of tissue donation more relevant and enables the patient to be involved in decisions about what happens to their body. Whilst palliative care health professionals thought it appropriate to approach patients regarding donation, thus supporting Spivey's (1998) study, they feared that raising the subject could cause distress and psychological harm. This was because talking about donation required the professional to broach the subject of the patient's death, an issue which even the hospice staff felt uncomfortable about. Furthermore, Wells and Sque (2002) found these issues and concerns were interwoven with the levels of knowledge and confidence the participants had about donation, which consequently affected their professional role in regard to donation.

Wells and Sque (2002) concluded that the unique ability of hospice patients to make their own decisions about donation had many implications and concerns for the health professionals who cared for them. They described this as the theory of 'Living Choice' which they defined as *"the ability of terminally ill patients within the palliative care environment to make choices about donation that have an impact on the knowledge and role of health professionals."* (p.24). The dominant core category is 'patient choice', meaning the patients' ability to be involved in the decision to be a donor. The other five categories are 'palliative care environment' - whether it is considered an appropriate clinical area for donation, 'professional role' - how this influences the decision making process, 'donation process' - issues relating to informing individuals about donation, 'concerns' - fear of causing distress to patients and family members and 'knowledge' - the requirements surrounding tissue donation. All the categories continuously interact to explain the commitment to tissue donation by hospices.

Although a small, qualitative study, Wells and Sque (2002) highlighted many issues for discussion and emphasised some of the differences between intensive care and hospices. Perhaps the most significant of these was the ability of patients within the latter environment to be involved in the decision making process about donation and the implications that this appeared to have on the professional role in facilitating donation. The findings of this study have been used as a basis for the development of this current work, building and expanding the views and opinions of health care professionals whilst acknowledging that there are other stakeholders who are involved in corneal donation within the hospice setting.

Many of the findings of Wells and Sque (2002) were confirmed and expanded on by Carey and Forbes (2003). Carey and Forbes (2003) explored the experiences, attitudes and feelings of family members who consented to donation of corneas within a hospice setting. Ten donor family members were interviewed four to 12 months after their family member's death. The findings indicated that the experience was considered positive by the donor families. It also showed that the majority of participants believed, due to cancer or old age, that their family member was ineligible for donation. Thus, had the subject not been raised with them by a health care professional, they would never have considered donation to be an option. The family members also indicated that donation decisions were easier if the patient's wishes were known prior to death. This study was small with data only collected from two hospices. However, the results gather important data on families' experiences.

A more recent study by Hughes (2005) explored the knowledge and attitudes of hospice patients towards organ and tissue donation. The purpose of the study was to identify patients' views about being informed about donation and the potential implications that this might have for practice. Eight patients attending a hospice day centre were invited to participate in face to face interviews. Subjects which were discussed included; their general attitudes towards organ and tissue donotransplantation, their knowledge of donation criteria, how they felt when the subject of donation was raised with them (and how they perceived other patients might feel), and their views about, when, how and who should provide information about being a potential donor.

A tentative new theory of 'Evocative Talk' was developed to explain the phenomena. The theory captured the essence of the data and was defined as: *"The nature of the organ/tissue donation discussion which, when raised with palliative care patients, assumes a greater significance than it might for other groups of patients or the general public and has the potential, therefore, to be hope-hindering, hope-enhancing or both"* (p38). The theory, as the definition suggests, highlighted that whilst donation discussion may be experienced very positively by patients, and have the potential to increase the donor pool, it may also cause distress by challenging patients' coping mechanisms, such as denial and hope, used to manage the threat of imminent death. Hughes (2005) concluded that whilst hospice health care professionals should not exclude donation discussion from important end-of-life issues that need to be discussed with patients, they need to develop strategies that will enable accurate judgements to be made regarding the appropriateness of raising the donation topic with individual patients. Again, this was a small study, with data only collected from one hospice day centre, therefore, it could be argued that the findings may not be transferable. However, as the only study that explores the views and attitudes of arguably the most important group, i.e. potential donors, the results can be used to support or refute further work.

All the research examined on organ and tissue donation in the palliative care setting have focused on specific homogeneous groups, for example Wells and Sque (2002) focused on health care professionals, Carey and Forbes (2003) considered the views of bereaved family members and Hughes (2005) examined the feelings of palliative care patients. What appears to be missing from the body of evidence is a study that captures the broader influences on tissue donation in the palliative care. Therefore, this study was developed not only to examine the views and feelings of stakeholders who have already been examined in previous studies (Hughes 2005; Carey and Forbes 2003; Wells and Sque 2002) but also those of other stakeholders, for example, corneal recipients, donotransplantation health care professionals, chaplaincy and bereavement services.

2.4 Summary

This chapter has provided an overview of hospices which are the setting for this study. It provided a critical appraisal of the development of specialist palliative care over the past 40 years. It focused on the debate surrounding the medical influences upon palliative care development and the ideology of what constitutes a good death including the political commitment to improve end of life care. This was followed by a critique of the current literature on tissue donation in hospices, highlighting the gaps, providing a rationale for this current study. The following chapter explores the methodology and methods used to implement the study.

Chapter Three:
Methodology and Methods

3.1 Introduction

This chapter presents the aim and objectives of the study. The study design will be discussed providing information on why a qualitative paradigm and grounded theory methodology were used to carry out this study. Strategies implemented for sampling and recruitment will be examined and how this was adapted during data collection to meet the aim of the study. A description of how data were analysed will be presented and the processes used to aid the development of a theory to explain the phenomena being studied. The use of a computer software package (NUD*IST 5), to store and work with data, will be explored, and the difficulties and solutions employed to tackle any problems will be examined.

Researching a group that is considered vulnerable raises many ethical issues. These issues will be explored followed by how the researcher perspective can affect rigour and trustworthiness and the strategies used within this study. Finally, how trustworthiness credibility and authenticity were maintained, will be examined.

3.1.1 Aim of the study

To explore corneal donation as an option to be discussed with patients and their families within the hospice setting.

3.1.2 Objectives

1. To explore the perceptions and feelings of stakeholders regarding corneal donation.
2. To identify methods of informing and discussing the option of corneal donation with patients and family members, and the pros and cons of those methods.
3. To establish what stakeholders perceive to be the effects of a discussion about corneal donation on patients and their families.
4. To explain stakeholders' behaviour in relation to corneal donation within the hospice setting.

3.2 Methodology

3.2.1 Philosophical perspective

Prior to embarking on a research study there needs to be a clear exposition of the philosophical premises that underpin methodological determination (Kelly and Long 2000). Paradigms or philosophical viewpoints influence the development of scientific knowledge. These paradigms provide an ontological perspective that guide epistemology and research approaches (Newman 1992). Quantitative and qualitative paradigms both contribute to the development of knowledge and exist on a continuum. Qualitative research facilitates theory building using words as a medium, whereas, quantitative research facilitates theory testing and uses numbers (Harper and Hartman 1997). The quantitative approach to research associates its philosophical viewpoint with the positivist paradigm, whereas, qualitative research is associated with the interpretive tradition.

The medical and nursing professions have largely focused their research on the medical model of treatment and its effectiveness, which is predominantly measurable (Holloway and Fulbrook 2001), and thus fits within the positivist research paradigm. Although medicine remains largely within the positivist paradigm, the field of nursing has more recently questioned its appropriateness within its own discipline where the voices and feelings of the client are of paramount importance. Clarke (1992) argues that some nurses find the quantitative research approach uncomfortable, unfamiliar and in many situations inappropriate for many research topics that are central to their clinical role. Indeed, the positivist philosophical viewpoint has been widely dismissed as incompatible for research into clinical practice, as it may deny the importance of subjective, psychosocial and spiritual elements of the nursing relationship with people (Clarke 1998). Within this study the voices of the stakeholders were vital.

If health care professionals are going to value the personal experiences and feelings of individuals, there is a need to employ research approaches that differ from the positivist methodologies and allow the collection and analysis of data which enable these phenomena to be studied. This has led to a shift towards the interpretivist approaches to research (Holloway and Fulbrook 2001). Bryman (2001) explains that the emphasis for interpretivists is the understanding of human behaviour, which is fundamental to clinical practice and within the scope of this study.

The interpretivist paradigm is based on a different set of philosophical assumptions to that of the positivist tradition particularly concerning the nature of reality. The positivist view that there is a single, objective reality or truth which can be discovered by scientific investigation is rejected by interpretivists who believe that truth is evasive and that humans construct their own view of a social world that has multiple, subjective realities (Clarke 1998). Munhall and Oiler (1986) argued that subjective and objective human realities are not mutually exclusive particularly within qualitative research.

Hospers (1990) discusses that experiences throughout an individual's life as well as social and physical environment will influence their identity and interpretation of the world. In their view humans interpret meaning through interaction, which is not standardised across social and cultural groups. If ontology is based on the assumption that reality is created in the mind and is socially and culturally based (Harper and Hartman 1997). This assumption allows for multiple interpretations of reality.

This multi-faceted reality allows the researcher to explore the interpretations and motivations, which underpin human behaviour (Kelly and Long 2000), and to positively facilitate intimacy and a means of uncovering information that can contribute to a profound understanding (Harper and Hartman 1997). The research participants' own perceptions, experiences and perspectives are allowed to develop. Therefore, knowledge is context driven and situation-related, meaning the researcher needs to have the skill and knowledge to be context–intelligent and perceptive of the social environment of participants.

The researcher's goal in this instance is to focus on the views, values, meanings, beliefs, thoughts and feelings of the research participants (Duffy 1987). This understanding of human behaviour can be gathered through the approaches of phenomenology, ethnography or grounded theory (Kelly and Long 2000; Lowenberg 1993). Essentially, the data are gathered by interviews, narratives, participant observation or documentary methods. One of the benefits of gathering data in these ways is the opportunity to obtain 'rich' data rather than responses directed along predetermined methods in which quantitative investigation depends (Holloway and Fulbrook 2001).

Qualitative research has been described as a collection of anecdotes and personal impressions, which is strongly subject to researcher bias (Mays and Pope 1995). Within quantitative studies the researcher is expected to adopt this already discussed objective, detached stance (Newman 1992). The reason for this is that if the researcher adopts this stance the phenomena being studied will show themselves as they exist, uncontaminated by a subjective bias that the researcher may bring to the data (Harper and Hartman 1997). However the qualitative approach positively encourages the researcher's values and life experiences as an important element in the interpretation of the data.

The researcher's ability to openly acknowledge and integrate their assumptions within a study is one of the reasons why qualitative research often encounters criticism. Researchers often neglect to provide adequate descriptions in their report of their assumptions and methods, particularly in relation to data analysis (Mays and Pope 1995). It is proposed that the researcher's own subjectivity becomes an analytic tool and is built into the research (Holloway 1997). Holloway (1997) suggests that researchers should be reflexive and aware of their own assumptions and to openly acknowledge their point of view within studies.

3.2.2 Grounded theory

Grounded theory was initially developed by sociologists Glaser and Strauss in 1965, when they embarked on research to explore the experiences of dying patients and their families (Glaser and Strauss 1965). They believed that to achieve the study aim of exploring the patients' experiences, an alternative approach to the traditional survey and questionnaire was required. Glaser and Strauss made the decision to develop a new approach to data collection and analysis, which would allow them to achieve their aim. This new research approach was later presented in the book, *The Discovery of Grounded Theory* (1967) and is now recognised as a seminal work (Charmaz 2006;

Cutcliffe 2005). Not only did they propose a method of developing theory from collected data, they also provided a discussion on the value of qualitative research.

Grounded theory is a qualitative research approach used to explore social processes within human interactions (Streubert and Carpenter 1999). It allows the researcher the opportunity to explain how individuals attempt to fit their lines of action to those of others, taking account of each others' acts, interpreting them and reorganising their own behaviour (Blumer 1969). This has been described as the interpretivist tradition of symbolic interactionism and is considered by Strauss and Corbin (1994) as being at the root of grounded theory methodology (Heath and Cowley 2004; Goulding 2002). The term was created by Herbert Blumer in 1937, who described symbolic interactionism as an approach, which focuses on the interaction between people, human behaviour and social roles. Mead (1934) also described 'self' as a social rather than a psychological being. He believed that individuals react to others and grasp their meanings through communication, gestures and facial expressions. In symbolic interactionism theory, it is believed individuals behave and interact according to how they interpret or give meaning to specific symbols in their lives, such as the meaning of corneal donation. Therefore, by interpreting communication and actions, individuals can choose from a selection of social roles. Morse and Field (1995) discuss that individuals construct their own realities of the world from the symbols around them, therefore people are active participants in creating meaning in a situation. Since its early development grounded theory, has been a methodology used to explain clinical practice (Benoliel 1996; Hutchinson 1993). Benoliel (1996) examined the contribution of grounded theory to nursing research since the 1960s and found that it had contributed to knowledge of how individuals adapt to illness, infertility, bereavement and nursing interventions, to mention just a few, which are key to nursing practice development.

What distinguishes grounded theory from other qualitative research approaches is that it specifically allows the researcher to develop a theory through a systematic method (Glaser 2005; Strauss and Corbin 1998; Glaser and Strauss 1967). This systematic method involves the simultaneous involvement in data collection and analysis throughout the research (Glaser 2005; Strauss and Corbin 1998; Glaser and Strauss 1967). Essentially, theory is generated inductively from the data, rather than from previous studies. Glaser and Strauss (1967) differentiated between two types of theory, substantive and formal. Substantive theory is developed from work in a specific area of inquiry (Goulding 2002; Streubert and Carpenter 1999; Glaser and Strauss 1967). It does not attempt to explain beyond the immediate field of study and should not try to generalise with explanations of issues where there are no data (Goulding 2002). Within nursing, Streubert and Carpenter (1999) give examples of substantive theory as client care, hope for clients and maintaining dignity. Whereas, formal theory has explanatory power across a variety of situations (Goulding 2002). Examples include organisational culture and power relationships (Streubert and Carpenter 1999). The purpose of this study was not suited to the development of a formal theory as according to Strauss and Corbin (1990) formal theory emerges from exploring a phenomenon in a variety of contexts. Therefore, a substantive theory was developed as the study is an empirical area of inquiry exploring corneal donation within the hospice setting.

According to Strauss and Corbin (1998) grounded theory involves "systematic techniques and procedures of analysis that enable the researcher to develop a substantive theory that meets the criteria for doing 'good' science" (p31). Strauss and Corbin (1994) describe theory as a plausible relationship among concepts and sets of concepts that can be traced back to the research data. As an inductive approach to research a grounded theory study does not begin with a theory, and then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge (Holloway and Wheeler 1996). The lack of a theoretical perspective to explain corneal donation in hospices required a research method that began with the phenomenon and assisted theory development.

Despite a long history of collaborative working, Glaser and Strauss over the years developed different ideas about how grounded theory should evolve (Box 3.1). Stern (1994) believed that their divergence of ideas was apparent in early work however, it culminated in Glaser (1992) writing a scathing account against Strauss and Corbin's (1990) adaptation to the 'classic' grounded theory approach. Glaser believed that Strauss and Corbin (1990) had distorted the meanings and principles of grounded theory and made it too prescriptive and rigid. Although, in later publications, Glaser (1978) provided researchers with further guidance on theoretical sampling, theoretical coding and theoretical memos, it was Strauss and Corbin's (1990) attempt to provide more detailed explanation of analytical techniques that caused Glaser to critique the work. Glaser (1992) believed that Strauss' approach could no longer be called grounded theory and that instead he had written about 'full conceptual description'. Glaser (1992: p122) described 'full conceptual description' as 'forcing the data', whereas he perceived grounded theory as a process of emergence, discovery and inductive theory generation.

Box 3.1 The different views of Glaser and Strauss

Glaser	**Strauss**
• Stresses the importance of interpretive, contextual and emergent nature of theory development. • Focuses on the data and allows it to tell the story. Theory develops directly from the data. • Argues that the theory is verified by returning to the data. • Rejects interpretivism. • Recommends a simple approach to theoretical sampling	• Emphasises the place of highly complex and systematic coding techniques. • Suggests that each word of the data is examined. • Recommends intricate tools for theoretical comparison. • Suggests many techniques for constant comparison. • Recommends a complex approach to theoretical sampling.

Heath and Cowley (2004) compared the Glaser and Strauss (1967) approach with that of Strauss and Corbin (1990) making it clear that they believe the two approaches should not be mixed. The reason given is that by attempting synthesis there is a risk of "violating philosophical underpinnings of both" (Heath and Cowley 2004: p147). The cautions in mixing the two approaches and the criticism of many studies that claim to use grounded theory (Morse 1991) has led to researchers hesitating in suggesting they used grounded theory. Instead many claim to be using a 'grounded theory approach' (Patton 2002) which means that the theory is grounded in the data.

When considering which methodological approach would be appropriate for this study, I remember reading that Glaser and Strauss (1967) recommend that grounded theory should have a creative element. Therefore, although I cannot claim to have used either approach in its purest form, I have carried out the simultaneous collection of data and analysis, constructed analytic codes and categories from data, used the constant comparative method, advanced theory development during each stage and used memo writing to elaborate categories.

3.3 Constructing grounded theory

The purpose of this section is to provide an understanding of how theory is constructed using a grounded theory approach, from the early stages of deciding an area of interest to study to data analysis and theory development.

3.3.1 Identifying an area of interest

As with any research, the researcher starts with an area of interest which needs further exploration. What makes researchers decide on using grounded theory is that generally there is limited literature and superficial attention in the area of interest (Goulding 2002). Consequently, the researcher starts with the area of interest and theory is allowed to develop from the 'ground'. To avoid preconceived ideas about the phenomena being studied, both Glaser (1995; 1992; 1978) and Strauss and Corbin (1998) discourage complete immersion in the literature. This is because the precise nature of the phenomena and how other researchers have interpreted it could colour the views of the researcher and the direction of the developing theory (Donovan 1995). Glaser (1995; 1992; 1978) suggests that grounded theory researchers should start their research without even deciding a question and by having just an "abstract wonderment" (Glaser 1992, p.22). Whereas, Strauss and Corbin (1998) believe that reading can take place around the phenomena but should be restricted to literature, as it will shape the initial data collection. This approach is supported by Willig (2001) who believes that some understanding and awareness of existing literature is necessary to ensure the issue is not already theoretically developed. The Strauss and Corbin (1998; 1990) approach to reading the literature was implemented for this study. Background reading of the literature in relation to the broader but related fields of organ donation and palliative care took place to ensure the study would contribute new knowledge, to obtain direction for the study and to be responsive to the participants' issues.

3.3.2 Data collection methods

Grounded theory data can be collected from a wide range of sources including interviews, focus groups, secondary data and observation. However, I only intend to discuss the two methods used during this study, face to face interviews and focus groups.

- Face-to-face interviews

By listening to the words of research participants the researcher can gain an understanding of the way individuals interpret the world and why they behave in certain ways (Holloway and Fulbrook 2001). Within interpretative research there are two interviewing techniques, unstructured and semi-structured (Robson 1993; Burgess 1984). The unstructured interview approach according to Burgess (1984) is a "conversation with a purpose" (p58). This approach allows the participant maximum control over the interview. Whereas, the semi-structured interview approach allows the researcher to keep the interview within defined perimeters, whilst providing the participant the freedom to express their opinion and the researcher the flexibility to ask for clarification and probe for further responses if necessary (Robson 1993). Within grounded theory the most common interview approach is the semi-structured approach (Charmaz 2006; Goulding 2002). According to Goulding (2002) the semi-structured approach is favoured as it allows the researcher to gather data which is rich and provides detailed accounts of the participants' experiences. This approach was used to gather data during Phase 1 of this study for the reasons discussed.

Interview guides are used to elicit ideas that need to be explored (Fielding and Thomas 2001; Kvale 1996). The use of the word 'guide' conveys the idea that researchers take their own path within certain guidelines. This contains broad topic areas but provides the researcher the freedom to probe and ask further questions if appropriate (Parahoo 1997). The broad topic areas allow the researcher an element of structure to the interview whilst enabling topics and perspectives to surface.

Fontana and Frey (1994) discuss the complexities of interviewing and provide a summary of issues to consider, which include: accessing the setting, understanding the language and culture of the participants, deciding on how to present oneself, locating a participant, gaining trust and establishing rapport. This allows some 'shared meaning' with the participant and the establishment of a rapport and a trusting relationship during the interview process (Fontana and Frey 1994).

- Focus Groups

Focus groups provide data and evidence that is not achieved through one-to-one interviews. Wilkinson (1999) argued that traditionally research with focus groups has tended to concentrate on the content, not dissimilar to one-to-one interviews, rather than the process of interaction. However, this led to alternative modes of analysis being recommended that included the group dynamics and the way individuals construct reality during the course of discussion (Webb and Kevern 2001; Bloor et al 2001; Kreuger and Casey 2000). Waterton and Wynne (1999) describe how focus groups provide the researcher insight into the "social processes of belief formation" and "relational construction of beliefs" (p127). They allow the researcher to capitalise on the interaction between research participants. Focus groups enabled participants to interact and comment on each other's experiences and responses.

Through the social interactions that take place during focus groups, participants are more likely to express emotion, debate with others, show anger and banter together, which is not generally evident in single interviews. According to Kreuger (1994) the interaction between participants is key to the focus group method of data collection and provides high levels of face validity as the participants are able to confirm, reinforce or contradict suggestions within the discussion.

3.3.3 Sampling

As grounded theory approach allows theory development, it is difficult to definitively predict the size and composition of the sample prior to the study. Charmaz (2006) suggest that the researcher should initially decide on the settings and on particular groups or individuals who are able to provide information on the topic being studied, this is called purposive sampling. In the early stages of data collection the researcher will go to the most obvious place and the most likely participant in search of information (Goulding 2002). Only when concepts are identified and the theory starts to develop will further participants need to be recruited to strengthen the findings

(Goulding 2002). This approach is called theoretical sampling, which Strauss and Corbin (1998 p201) describe as:

> *"Data gathering driven by concepts derived from the evolving theory and based on the concept of "making comparisons," whose purpose is to go to places, people or events that will maximize opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions."*

In principle this means sampling is guided by ideas, which have significance for the developing theory. According to Strauss and Corbin (1990) the aim of theoretical sampling is to sample events and incidents that are indicative of categories, their properties and dimension, so that they can develop and be conceptually related. This means that theoretical sampling involves the selection of participants on the basis of their relevance to the theoretical development of a study. Grounded theory's emphasis on discovery indicates the need for an open, unstructured approach to research in which, new opportunities for data collection can be realised as the study takes shape (Charmaz 2006).

3.3.4 Data analysis

There are key elements of data analysis which are typical of grounded theory. The initial stage of data analysis is called **open coding** and takes place at the beginning of a study. In general, open coding starts with transcription of an interview followed by line-by-line coding. This is the process where data is analysed line-by-line in an attempt to identify key words or phrases which give insight into the phenomena being studied. By coding each line of data, it allows the researcher to decide where to collect further data (Charmaz 2006).

When using a grounded theory approach analysis takes place at the same time as data is collected rather than waiting till all the information is gathered. It is the process of breaking down the data into separate units of meaning (Goulding 1999). Strauss and Corbin (1990) describe it as "the process of breaking down, examining, comparing, conceptualizing and categorizing data" (p61). Essentially, the main purpose of open coding is to conceptualise and label data. The initial stages of coding should be kept open, unfocused and close to the data. Charmaz (2006) suggests that researchers should code words that reflect actions, rather than topics, to curb the tendency to make conceptual leaps and adopt extant theories at an early stage.

During this stage hundreds of codes or concepts may be identified which have potential meaning and relevance (Goulding 1999). Charmaz (2006) proposes that the openness of initial coding should spark the researcher's thinking and allow new ideas to develop. The aim is to follow up on concepts that indicate that they fit the data and then gather further data to explore and expand these. This is the constant comparative method. The constant comparative method is fundamental to data analysis when using a grounded theory approach with data collection and analysis taking place simultaneously (Blaikie 1993). It is a step-by-step analytic method, which allows sense to be made of qualitative data, facilitating the identification of concepts, which are grounded in the data (Strauss and Corbin 1998; 1990; Glaser and Strauss 1967). It entails the comparison of incident with incident to look for patterns and concepts (Goulding 2002; Holloway and Wheeler 1996). Strauss and Corbin (1998) describe how concepts are more than just describing what is in the data. They explain the link between and across incidents that need to be checked against each other to confirm understanding (Dey 1999).

One of the skills of grounded theory analysis is being able to identify data gaps and to identify where to source this data. This is achieved through theoretical sampling. At the stage of open coding, sampling should be selective and focus on developing themes. Glaser (1978) stresses that although the researcher should become more focused, they should also be prepared to stay open to the possibility of new ideas and therefore, be prepared to adapt to these changes. By simultaneously collecting and analysing data the researcher is able to delve further and deeper into the research phenomena, whilst engaging in category development (Goulding 2002).

Once patterns occur, the concepts are clustered into groups to form categories. A category is discovered when concepts are compared with one another and appear to relate to a similar phenomena (Strauss and Corbin 1998). Goulding (2002) describes how "categories are higher order concepts. They have much wider explanatory power, and pull together all the identified concepts into a theoretical framework" (p77).

These categories are given abstract titles, which are logical descriptors of the grouped concepts.

During this level of coding, theoretical saturation should be reached. Saturation is reached when no new information is being collected during coding. In other words, if when the data is being examined only recurrent concepts are discovered and coded the category can then be termed saturated. However, Strauss and Corbin (1998) believe there will always be new information to be discovered. They believe that saturation is more about reaching the point where the collection of more data seems counterproductive, and that new information would not add to the explanation at that time.

The next stage of analysis is **axial coding** (Strauss and Corbin 1998; 1990). Charmaz (2006) describes how axial coding "relates categories to subcategories, specifies the properties and dimensions of a category, and reassembles the data you have fractured during open coding to give coherence to the emerging analysis" (p60). Axial coding enables the researcher to answer questions such as "when, where, why, who, how and with what consequences" (Strauss and Corbin 1998 p125).

The final stage of analysis is **selective coding** (Strauss and Corbin 1998; 1990). Strauss and Corbin (1998) describe this as the process of integrating and refining categories to form a theory. The initial step of integration is deciding on a core category. This is a representation of the main theme of the research and then systematically relating it to other categories (Strauss and Corbin 1998). Essentially, "it consists of all the products of analysis condensed into a few words that seems to explain what the research is about" (Strauss and Corbin 1998 p146). The core category is the central idea which relates to all the other categories (Strauss and Corbin 1990). After deciding the core category and positioning it at the centre of the process being explored other categories are identified to illustrate the context (structure) and the process of the phenomenon (Strauss and Corbin 1990). Through selective coding the categories are integrated and developed into a theory. Strauss and Corbin (1998) discuss how a theory should be generated around a core category. The technique used to identify the core category and the integration of other categories to generate theory was achieved through the use of a story line.

3.4 Methods

3.4.1 Sampling and Recruitment

Each Hospice and health organisation, where participants were recruited, was visited and the aim of the study discussed. Permission to recruit participants was requested from heads of service in each organisation and subsequently agreed in writing.

Seventeen participants were recruited to be interviewed and thirteen participants, in total, recruited for the two focus groups. Participants who were employed or involved with palliative care were recruited from three hospices (Table 3.1). They were recruited as they were key stakeholders in corneal donation within the hospice settings. The title, number and codes of participants in the interviews and focus groups are listed in Table 3.2 and 3.3.

Table 3.1 Participating Hospices

	Number of beds	**Status**
Hospice 1	26	Voluntary
Hospice 2	10	Voluntary
Hospice 3	8	NHS

Table 3.2 Interview participants and numbers

Participants	**Number**
Hospice Nurses *(Their grade and experience varied).*	2
Hospice Doctors *(Consultants in Palliative Medicine)*	2
Chaplains *(1 Church of English Chaplain, 1 Rabbi)*	2
Social Worker *(Employed by Hospice)*	1
Patients *(Known by a Community Palliative Care Nurse)*	2
Bereaved Family Members *(Had agreed to the donation of a family member's corneas, who had died in a hospice during the previous year).*	2
Corneal Recipients *(Had received a corneal transplant within the previous eight months)*	2
Donotransplant Coordinators	2
Eye Bank Coordinator	1
Ophthalmic Surgeon	1

Table 3.3 Focus group participants, numbers and their codes

Code	**Participants**	**Number**
FG1	Hospice Doctors *(1 Palliative Medicine Consultant, 1 Staff Grade Doctor)*	2
	Hospice Nurses *(All with at least 5 years palliative care experience)*	4
FG2	Chaplain	1
	Chaplaincy Volunteers	2
	Social Workers	2
	Volunteer Bereavement Counsellors	2

The sample groups were chosen to gain a wide view of the phenomenon. It was essential that individuals who had a stake in the corneal donation process were able to contribute their experiences, feelings, attitudes, and beliefs to provide rich data. A list was initially formulated of who I considered were the key stakeholders. They were divided into four key stakeholder groups (Appendix 5). The first and second groups were employed within hospices. The third group consisted of health care professionals who did not work within a hospice setting but had a contribution to the corneal donation decision making process. The fourth group consisted of patients and bereaved family members who had given a 'lack of objection' for a deceased family member who had died in a hospice, to donate their corneas. It was not intended that this should be an exhaustive or prescriptive list, and it changed during data collection. Thus, in the early stages of data collection a purposive sampling approach was used but changed to theoretical sampling during further data collection and theory development, to enable saturation.

Phase 1: Interviews

Group 1, 2 and 3 Recruitment.

A poster was developed and displayed in the three hospices inviting nurses, doctors, social workers and chaplains to participate. They were requested to contact me for further information. On their enquiry an information sheet (Appendix 6) explaining the study was sent to them. A reply slip of agreement to participate in the study (Appendix 7) and stamped addressed envelope was also provided, with the information sheet explaining the study, for return to the researcher. Once I had recruited the required number for the study (Table 3.2), the poster was removed. The donotransplant coordinators, an ophthalmic surgeon and an eye bank coordinator were invited from specific hospitals as they provided a service for the three hospices. All participants who requested an information sheet agreed to participate.

Group 4 recruitment

Bereaved family members who had consented in the previous year to corneal donation within the hospice setting were recruited to the study by community palliative care nurses from Hospice 1. After discussion with the bereavement services at Hospice 1, it was decided that I should invite bereaved family members whose family member had died within the previous year, as if any longer, the experience may not be as clear and memorable to them. Also, I was conscious to avoid significant dates, i.e. the anniversary of the family members' death or birthdays to reduce the risk of causing further distress. The community palliative care nurse who knew the bereaved family members contacted them by telephone or by a visit to explain the study and offered them the option of receiving an information sheet (Appendix 8). This introduced myself and explained the aim, participant's contribution and any benefits of the study. A reply slip (Appendix 9) and stamped addressed envelope was provided for return to the researcher. It was important that the nurse who made contact with the bereaved family member was known to them to assure me that they had been fully informed about the study and that their decision was voluntary. When two families had agreed to participate I informed the community palliative care nurses that they did not need to approach any more families.

Patients with a life limiting illness were also recruited from Hospice 1, by the community palliative care nurses. They approached patients, about the study, who had previously discussed end of life issues. If any patient expressed interest they were given a participant information sheet (Appendix 10), reply slip (Appendix 11) and stamped addressed envelope for return to the researcher. The following criteria for recruitment of patient participants were used:

- Alert, to ensure an understanding of the questions and to provide informed consent.
- The ability to communicate with the researcher.
- At the time of the study to have no contra-indications for corneal donation.

Once two patients agreed to participate I informed the community palliative care nurses that they could stop recruitment.

Recipients of corneas were recruited by an ophthalmic surgeon who discussed the study with patients who had returned to outpatients for an appointment following corneal transplantation. If they wished to consider participating in the study they were given a participant information sheet (Appendix 12), with a reply slip (Appendix 13) and stamped addressed envelope for return to the researcher. Both participants had received their corneal transplant or transplants within the previous year.

All participants were contacted by telephone to arrange a convenient time and venue for the interview and to give them the opportunity to ask further questions. This was confirmed in writing (Appendix 14). All the interviews took place in the participants' work environment except the palliative care patients, bereaved family members and recipients of corneas. They were offered the option of attending the hospice or for me to visit their homes. They all requested that I visit their homes.

Phase 2: Focus Groups

Two focus groups took place with:

1. Nurses and doctors who worked at Hospice 1 and 3.
2. Bereavement counsellors, social workers, chaplains and chaplaincy volunteers who worked at Hospice 1 and 3.

As with the interviews a poster was developed and displayed in all three Hospices inviting individuals to participate. At individual's request an information sheet (Appendix 15) explaining the study was sent to them. A reply slip (Appendix 16) and stamped addressed envelope was provided for return to the researcher. When a sufficient number (n=6-8) and combination of stakeholders agreed to participate the posters were removed. At Hospice 2, there was no interest from individuals to take part in the study.

A selection of dates and times were sent to each participant to identify the most convenient time for the focus group. Each participant was then informed in writing of the date, time and venue (Appendix 17).

3.4.2 Pilot studies

To reduce the risk of collecting poor, irrelevant data, a pilot study was carried out with two nurses, who worked in hospices, for Phase 1 and one focus group for Phase

2. The aim of the pilot study was to ascertain whether the interview guide was appropriate and understandable. It also gave me the opportunity to test the dictaphone, to become more confident in performing interviews and focus groups and to practice responding to cues that were raised by the participants.

The pilot interviews highlighted the need to acquire a room that was quiet and where the interview could be carried out free of interruptions. This led to better preparation and consideration of the environment for subsequent interviews. Several reasons led to my decision to use the data collected within the pilot focus group for the main study. This included the logistical difficulties of arranging and getting participants together, previous experience and confidence in the facilitation of focus groups and a desire to use the valuable data that was collected from participants.

3.4.3 Data Collection

Data was collected in two phases.

Phase 1- Semi-structured face to face interviews with key stakeholders.

Phase 2- Focus groups to expand on the findings of the interviews.

The findings of Phase 1 helped to develop the discussion for Phase 2 (n=2) focus groups.

- *Interviews*

In Phase 1, the data were collected by inviting participants to be interviewed using an interview guide (Appendix 18). The aim was to collect detailed accounts of participants' experiences, views and feelings regarding corneal donation. Open-ended questions were used to provide participants with the maximum opportunity to expand on their answers and were reviewed and changed after each interview depending on the findings from the previous interview.

The flexibility of the semi-structured interviews allowed the phrasing and order of questions to be changed, which was dictated by participants' experiences and responses. This was important within Phase 1 of this study as the sample included participants from a variety of backgrounds. Therefore, participants' background and experience of corneal donation and palliative care determined the focus of each interview.

Participant permission was sought to use a dictaphone to record both the interviews and focus groups. This allowed collected data to be as accurate as possible, and enabled me to concentrate on the interview process and listen to what participants were saying. To reduce the risk of problems occurring with the dictaphone and subsequently loss of data, two dictaphones were used and the batteries were changed prior to each interview or focus group.

- *Focus groups*

The findings of Phase 1, determined the structure and direction of Phase 2, as issues raised from the interviews were used to direct the discussion within the focus groups. It was decided to have participants within the focus group who were from homogenous groups. The focus groups were divided into two distinctive groups of stakeholders. This was done for pragmatic reasons. I decided to run FG1 with palliative care health professionals (nurses and doctors). FG2 was run with other members of the multi disciplinary team (chaplaincy and bereavement team members) who provide supportive care. Clinical background, relationships between participants and possible power struggles were considered within the context of this study. It was a decision based on the principle that the corneal donotransplantation process involves individuals with different roles and backgrounds. I also decided to invite stakeholders from different hospices to enable further interaction and discussion on different approaches. A schedule was used for each of the focus groups (Appendix 19 and 20).

To ensure the relationships and interactions between participants were captured during this study, sections of transcript have been integrated within the findings to provide the reader with the dynamics and discussions that were present during the focus groups and how this relationship influenced analysis and theory development. The purpose of including focus groups within this study design was as discussed, to confirm, reinforce or contradict ideas that had been raised during the initial interviews through interaction, discussion and debate.

I moderated the focus groups, which involved ensuring the comfort of the participants, including confidentiality, facilitating the development of the discussion and ensuring participation. An observer, who is a colleague with experience of facilitating focus groups, was recruited for both the focus groups to document interactions and reactions of participants. Each of the focus groups were held at a hospice and lasted no longer than one hour.

*3.4.4 Use of NUD*IST 5 software programme*

As data were collected and transcribed during the study, it was inserted into a computer assisted qualitative data analysis software (CAQDAS) package. The CAQDAS I chose to use was NUD*IST 5. This decision was based on what was available through my workplace and having access to basic training through the University. At first glance, it appeared to be a software package that would 'resolve my concerns' and make the management of data less time consuming and more visual and organised. However, it soon became apparent that there were limitations to only using NUD*IST 5 to store and work with data during this study.

Once I had become familiar with using NUD*IST 5, coding of data were quicker and more organised however, what became difficult was visualising the development of concepts and categories and the emerging theory. When using grounded theory, there is a need for constant comparison between data throughout analysis, which was difficult to conceptualise using only NUD*IST 5. Therefore, I decided to apply a joint approach by using both the computer software and manual method. NUD*IST 5 was used to store and assist with coding the data. Whilst, the commonly used approach of coloured pens, 'post-its', cut up pieces of paper and a white board were used to assist category development. This approach made it easier to visualise and conceptualise analysis. Much of the early frustrations of endeavouring to only use NUD*IST 5 is evident in my study journal and the initial thoughts that took place to appreciate the need to use a joint approach. The decision was made after five interviews had taken place and after many hours trying to refrain from taking this step. This joint approach to data analysis is supported by Lee and Fielding (1995) who suggest that many researchers confine their use of CAQDAS to coding and retrieval and that theory development is done in the mind or on paper.

There has been much debate over recent years about the use of CAQDAS to assist the researcher in working with large volumes of qualitative information and data (Charmaz 2006, 2003; Goulding 2002; Seale 2000; Richards and Richards 1994), particularly with the growing number of available software packages. Advocates of NUD*IST 5 claim that it eases the arduous and time consuming process of identifying and cross-checking concept development (Richards and Richards 1994). Richards and Richards (1991) suggest that NUD*IST 5 provides the researcher with the tools to transcend code and retrieval to incorporate the handling of transcripts, notebooks and text and unit indexing. Also, NUD*IST 5 facilitates the researcher the opportunity to change the content of categories. An additional advantage of using CAQDAS is discussed by Seale (2000) who suggests that by using software packages the researcher can demonstrate that their conclusions are based on rigorous analysis.

Richards and Richards (1994) warn that researchers should be cautious of the limitations of CAQDAS. They believe there is a danger that data may be reduced to codable data but that the richness and valuable sources of theory development may be lost. This was an area I was concerned about and that the creativity would be lost. Dembrowski and Hammer-lloyd (1995) discuss how they fear that by using CAQDAS packages there is a risk of qualitative data analysis becoming too mechanistic potentially leading to a loss of the wider picture and non-textual sources of data analysis. However what needs to be remembered is that CAQDAS does not carry out the analysis or 'build the theory' this is the work of the researcher's own intuition and thinking (Seale 2000).

3.4.5 Memos

An important element of grounded theory analysis is the use of memos. Glaser (1978) believes that memos are an essential part of the research process and without using them theoretically the researcher cannot profess to using grounded theory. Memos are described as "the researcher's record of analysis, thoughts, interpretations, questions, and directions for further data analysis" (Strauss and Corbin 1998, p110). Essentially memos are ideas and concepts that the researcher collates during data analysis to assist with the development and formation of theory. There is no right or wrong way to write and present memos. It is suggested that the researcher be guided by an approach that gives meaning and is understandable and helpful to them (Strauss and Corbin 1998; Glaser 1978).

NUD*IST 5 qualitative software package has the capacity to write and store memos. Initially, the memo was used to remind me of things to do. As data analysis developed this changed and the approach to use of memos became more complex and crucial to data analysis. Box 3.2 shows an example of a memo written during the earlier stages (Interview 3) of data collection and analysis.

Box 3.2 Example of memo

Oct 3, 2003 Nurse A

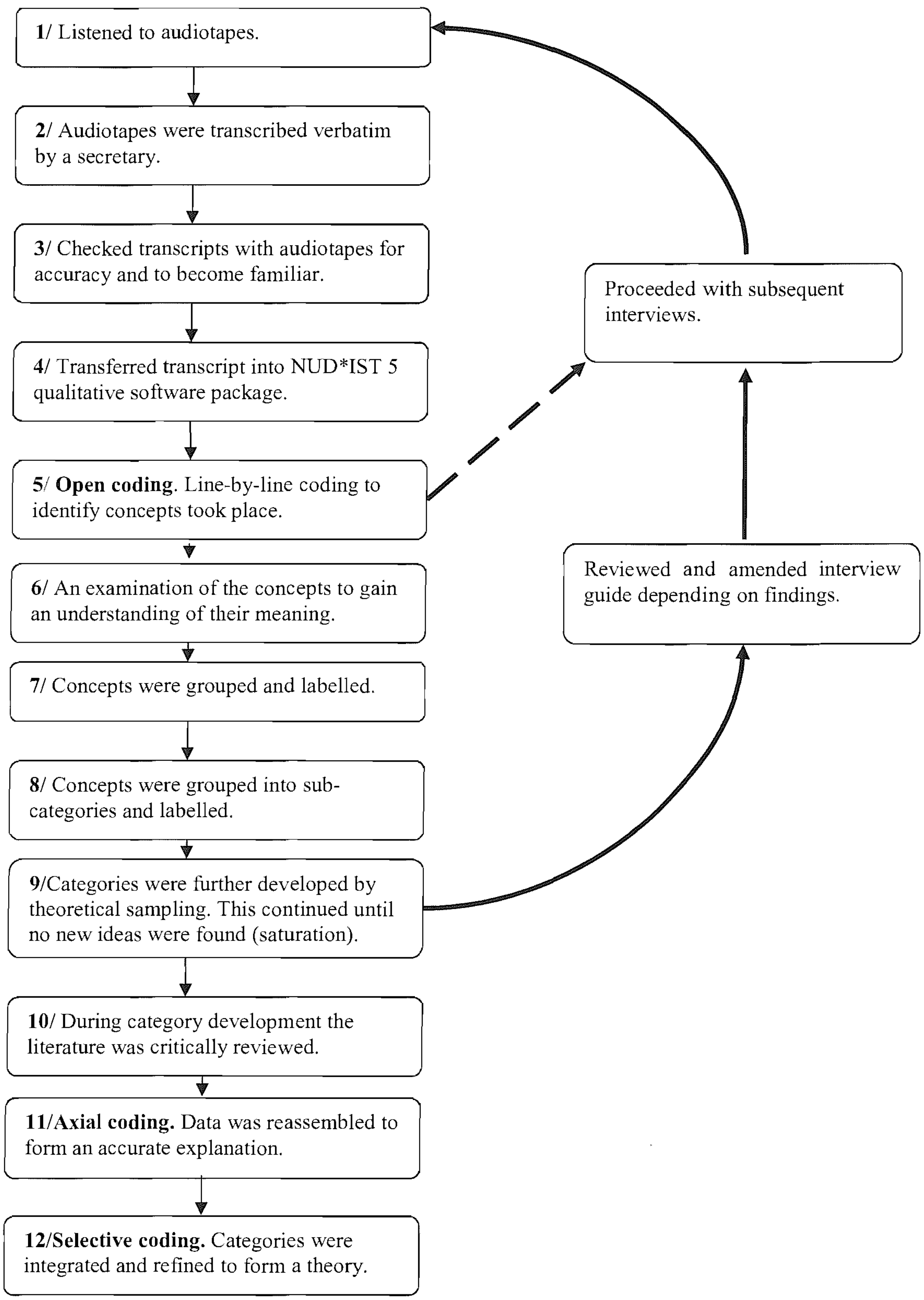
'I don't want to upset the patient or family'. Upset and the emotional consequences of discussing corneal donation appear to be a common theme. Whether this is actual or anticipated reaction I will explore in the next interview. What do they mean by upset? Is the upset due to the general situation of their family member dying or purely because of the discussion about donation?

3.4.6 Data analysis

Data analysis consisted of a series of steps to be followed so that I could make sense of the data. It involved the collection of data, coding, category identification and theory development. The analysis of the data was ongoing throughout the study using the constant comparative method initially discussed by Glaser and Strauss (1967).

Strauss and Corbin (1998) wrote about the stages in the development of grounded theory research, but emphasized that this is not a prescriptive process for researchers to adhere but believe that researchers should be creative and flexible in their approach whilst staying true to the data. The next section examines the stages of analysis used within this study with reference to Figure 3.1.

Figure 3.1 Stages of data analysis.



Stages of Analysis

1) After each interview was carried out I replayed the audiotapes and listened to them several times to get an understanding and 'feel' for the interview data.

2) I then transcribed the audiotapes verbatim after each interview to ensure accurate documentation of the data.

3) I listened to the audiotapes several times with the transcript to ensure accuracy and to become more familiar with the data. It was important to me that stages 1, 2 and 3 were completed as soon after the interviews as possible to ensure the meaning of the data and thoughts of the participants remained clear. I completed this stage of analysis within three-four weeks of each interview.

4) I transferred the transcribed data into a qualitative software package (NUD*IST 5). NUD*IST 5 facilitated working with the data and supported the analysis process.

5) The next stage of the analysis was **open coding** of the data. In broad terms this is described as the breaking down of data into discrete parts and writing impressions and ideas (McCann and Clark 2003). These are called concepts or codes, which are single events that are related to a phenomenon (Strauss and Corbin 1998). The phenomenon in this case was corneal donation within the hospice setting. The concepts which were related to the phenomenon I identified through line-by-line coding of raw data (Appendix 21). Stages 6-12 of data analysis, from breaking data apart to theory development, will now be explained using the example of the category 'Being'.

6) During the next stage I examined the data carefully to gain an understanding of what the concepts meant for the participants and for development of their properties and dimensions. This procedure was assisted by memo writing (section 3.4.5.) This took place to a small extent within the initial stage of coding (Stage 5). Strauss and Corbin (1998) call this process 'microanalysis'. This allowed me to break the data apart and explore words and statements for

potential meanings (Figure 3.2). In examining the open coding there were several examples where participants mentioned the **afterlife**.

Figure 3.2 Breaking the data apart and memo writing

Comment referring to afterlife

"I was always told that I needed my eyes after I've died." (Nurse A: 411-412)

Memoing

Always told- Always could mean 'being told over and over again by others either in the same or similar form'. By always being told could have caused fixed or undecided behaviour.

To be told could infer that this occurred by speech or in writing. It could have been intended as a warning, a story or a person's views.

Needed my eyes- by using the word 'need' it makes it a requirement or it is essential to maintain a visual sense after death.

7) I labelled the concepts to group similar findings. These were labelled using concepts or words used by the participants. Codes arising directly from the words of participants have been described as 'in-vivo' codes (Strauss and Corbin 1998; Glaser and Strauss 1967). For example, as shown below there were several references to the afterlife, which have been grouped together into the concept group, 'Afterlife' (Figure 3.3). During subsequent analysis if data alluded to the same issue I grouped them into the same concept group. A total of 87 concept groupings were identified.

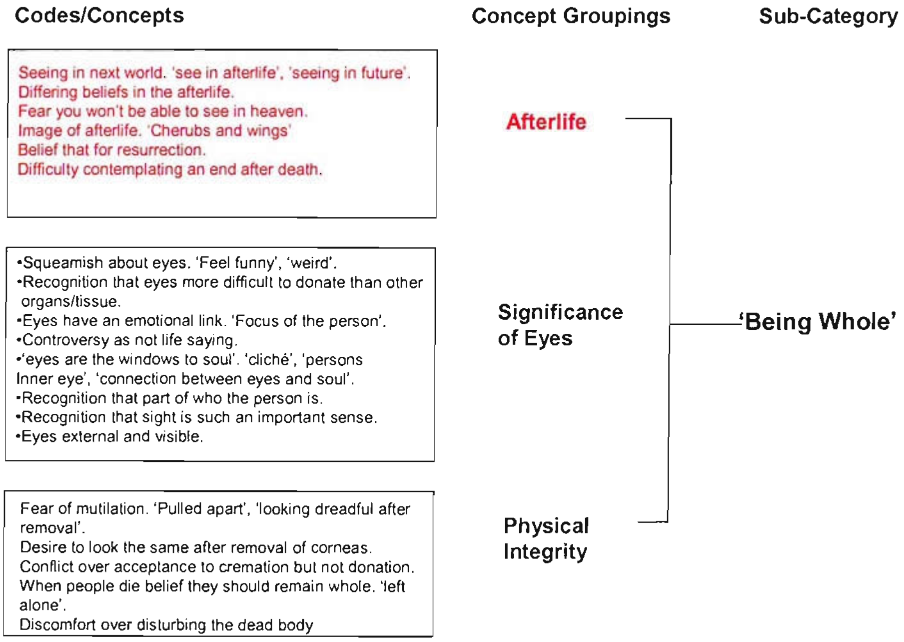
Figure 3.3 Concept grouping: 'Afterlife'

Seeing in next world. 'See in afterlife'. 'Seeing in future.
Differing beliefs in the afterlife.
Fear you won't be able to see in heaven.
Image of afterlife. 'Cherubs and wings'.
Belief that for resurrection.
Difficulty contemplating an end after death.

Afterlife

8) Once concept groupings were labelled I began a process of integrating these to form sub-categories. Sub-categories are conceptual characteristics of a category (Goulding 2002). An example of this process can be seen in the sub-category ‘Being whole’ (Figure 3.4). I labelled the sub-category ‘Being whole’, as after examining the concept groupings ‘Afterlife’, ‘Significance of Eyes’ and ‘Physical Integrity’ and identifying there were logical and common themes across the concept groupings which related to the significance of an individual remaining intact and whole after their death.

Figure 3.4 Sub-category development: ‘Being whole’



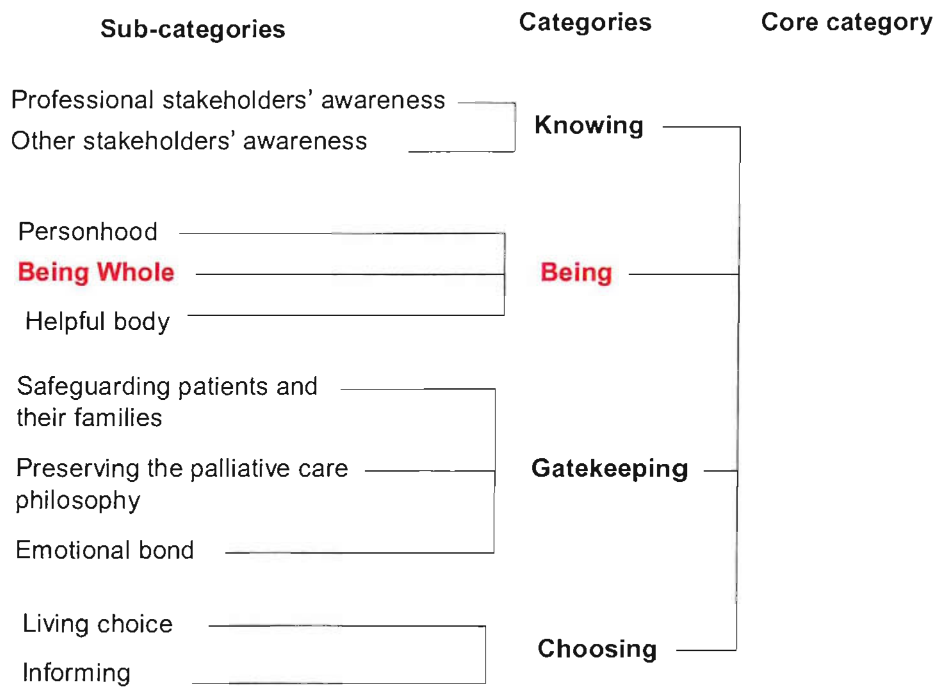
9) I further developed the categories by theoretical sampling. I constantly compared the categories in subsequent interviews until I reached the stage where no new information was found. For example, when participants no longer provided new information on the ‘afterlife’, no further data was collected. This is the stage of saturation and occurred at different times for each category (Strauss and Corbin 1998).

10) During category development I critically reviewed the relevant literature. Strauss and Corbin (1998) suggest that selective review of the literature should

be woven into the stage when the theory is being developed. An example of this was a review of literature relating to the religious significance and meaning of the term 'life after death'.

11) At this stage a process of **axial coding** begun. I integrated categories and sub-categories to form accurate and complete explanations of the phenomena being studied (Strauss and Corbin 1998) (Figure 3.5). This was achieved by initially identifying the properties and dimensions of the categories and secondly, by hypothesising the relationships and interactions between categories and sub-categories (Strauss 1987). At this stage all the sub-categories that had been developed were examined to identify interactions. The sub-categories 'Being whole', 'Personhood' and Helpful Body' all had a common relationship which reflected the nature and existence of a person. This led me to label the category 'Being'. This stage formed the basis for theory generation.

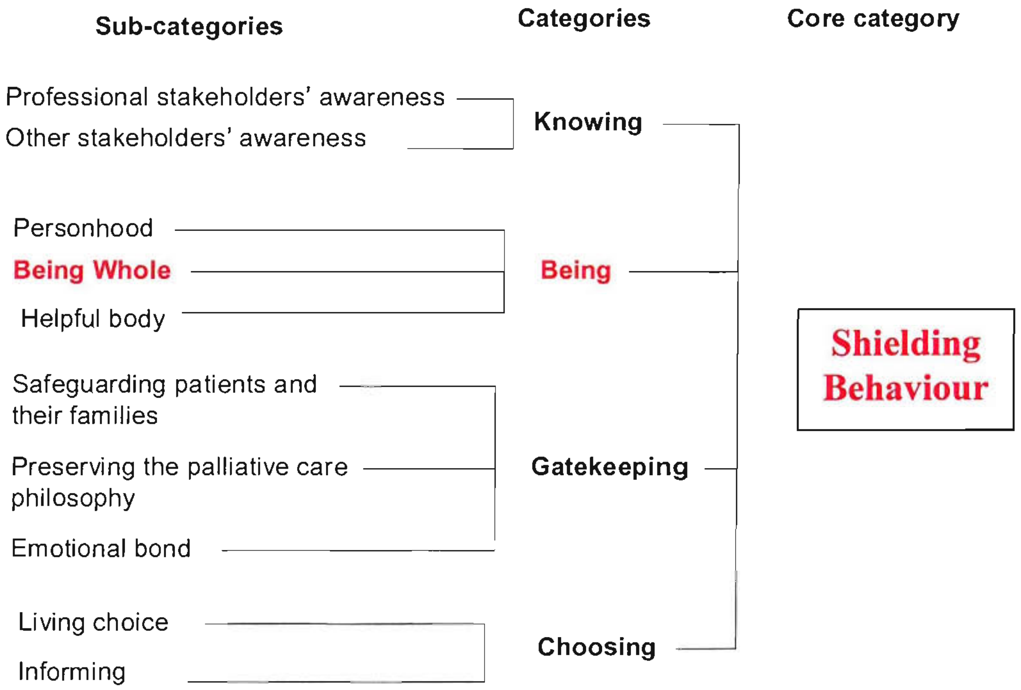
Figure 3.5 Integration of categories and sub-categories



12) a) The final stage was **selective coding,** which was the process of integrating and refining the categories to form a theory. Identifying the core category of

‘Shielding Behaviour’ was the initial stage (Figure 3.6). According to Glaser (1978), the core category is a main theme within the data, linking all other categories and providing an overarching explanation of the social process within the data. ‘Shielding Behaviour’ was identified as the core category as it explained the behaviour which linked all the other categories together.

Figure 3.6 Core category development



b) I then developed a diagrammatic model which represented the theory of ‘Shielding Behaviour’ (Figure 4.1, p74).

3.5 Ethical considerations

The researcher has a personal and professional obligation to ensure protection of the participants against physical, emotional, mental and social injury (Cormack 1991). Health care professionals and ethics committees are often over protective of dying patients and bereaved family members particularly when considering their participation in research. Even when ethical principles are ensured, there has been a lot of discussion and controversy within palliative care whether research within the field is moral or appropriate due to the burden that may be placed on this group of patients and their families (Ewing et al 2004; Lee and Kristjanson 2003; Illhardt and Have 2002). According to Illhardt and Have (2002) this attitude has led to a low research output in the field of palliative care in comparison to other disciplines. Ethical approval from a Multi-Regional Ethics Committee (MREC) was sought and agreed (Appendix 22) for this study with no amendments required. Local Research Ethics Committees and Research and Development Departments in each organisation were also informed and agreed to host the study.

A theoretical framework proposed by Foster (2001) was used to consider the ethics for this study. The ethical model consists of three parts: goal-based morality, duty-based morality and right-based morality.

3.5.1 Goal-Based Morality

Goal-based morality assumes that the research being undertaken is important enough to maximise wellbeing whilst minimising any harm (Foster 2001). This focuses on the principles of utilitarianism by Jeremy Bentham (1748-1932) whereby an action's consequences determine whether the action itself is right or not. To determine what would be the value of corneal donation within palliative care, meant that research needed to take place to explore participants' views on the issue.

However, Foster (2001) argues that a utilitarian approach only considers the outcome and does not take into consideration the process. Therefore, this approach could in essence allow immoral research as long as the outcome maximises health. For research on humans to be ethical not only does the outcome of the research need to be considered but also that the methodology is appropriate and will cause minimal risk to the participants.

3.5.2 Duty-Based Morality

Duty based morality is concerned predominantly with the content and process of the research rather than the results. Therefore, even if the expected results will be important to health care, if the way this evidence is gained will cause harm to the participants then the research is considered unethical (Foster 2001). Also, duty-based principles work on the premise that research with humans will benefit and not harm research participants (Foster 2001). Palliative care patients will often not directly benefit from the research they are participating in, as they will often die before the research is complete. de Raeve (1994) questions what patients with life limiting illnesses gain from taking part in research and ultimately whether they should be participants. However, palliative care patients have a right to choose whether they participate in a study, which may benefit future patients. Lee and Kristjanson (2003), suggest that to refuse a patient with a life limiting illness the choice to participate in research is essentially denying them the opportunity to have an active role in living and will prevent them from contributing to increasing knowledge.

Due to the sensitive nature of the subject, and the participants who were being interviewed, there was the potential for issues to be discussed that could lead to further support being required. Therefore, post interview support was made available by the researcher or if necessary organised with the participating organisations. All participants were informed of this option verbally before the interviews and focus groups took place and it was written in the information sheets (Appendix 6, 8, 10, 12, and 15).

3.5.3 Right-Based Morality

The right-based principle requires that all people who participate in research should do so only after they have consented to take part and that the researcher should respect the participants' confidentiality (Foster 2001).

Obtaining informed consent from participants when undertaking a study is ethically essential (de Vries 2006). Consent needs to be voluntary and should only be gained if participants are given relevant information. Patients, families and health care professionals participated in the data collection, therefore informed consent was essential. An information sheet was devised for each of the participating groups, as their information needs were different. At the beginning of each interview or focus group I went through the information sheet to ensure participants had no questions and were happy to proceed. At this stage participants were asked to sign a consent form (Appendix 23).

It was important that participants were given the opportunity to withdraw at any time, particularly with regards to the palliative care patients, whose conditions can change very suddenly. It was important that I was sensitive to changes in the patients' conditions and to offer them the opportunity to withdraw. It has been suggested that patients with life limiting illnesses and families feel obliged to participate in research, in gratitude for the care they have received and as they want to please those that are providing the care (Seymour and Ingleton 1999). To avoid this happening, gatekeepers were used within the clinical areas to recruit participants, and I was not involved in the care of recruited patients or families.

Confidentiality and anonymity for the participants was essential and was respected within the study. When more than one participant represents a group they were identified in alphabetical order, for example Nurse A, Nurse B. Audiotapes and transcripts were coded using identifiers and stored separately from the consent forms, to ensure anonymity for the participants. The audiotapes, software back ups and transcripts will be stored for 15 years and then destroyed in accordance with The University of Southampton policy.

3.6 Researcher perspective

By using grounded theory there is a constant interplay between the researcher and the research process (Strauss and Corbin 1998). According to Strauss and Corbin (1998) because this interplay requires immersion in the data, by the end of a study the researcher is shaped by the data, just as the data is shaped by the researcher. This immersion in the data requires the researcher to consider how they intend to maintain a balance between objectivity and sensitivity, when both are required for discovery and theory development (Strauss and Corbin 1998; Glaser and Strauss 1967).

To maintain this balance between objectivity and sensitivity requires a reflexive approach to the research process, requiring the researcher to acknowledge themself as an intrinsic part of the research. This acknowledgement represents part of 'theoretical sensitivity' (Strauss and Corbin 1998; Glaser and Strauss 1967). Theoretical sensitivity refers to the ability of the researcher "to respond to the subtle nuances of, and cues to, meanings in data" (Strauss and Corbin 1998 p35).

As a nurse working within a hospice setting, whilst undertaking this study, it was not possible for me to remain completely impartial and divorce myself from the knowledge I have gained. Theoretical sensitivity was present by virtue of my professional experience. This insight provided me with a comparative base for asking questions and allowed me to give meaning to the events expressed in the data (Strauss and Corbin 1998). A study journal was used throughout to reflect on my own personal views and interpretations of the collected data and will be discussed further within the section on trustworthiness.

Theoretical sensitivity is also achieved by reading the literature as it sensitises the researcher to relevant and significant parts of the data (Holloway and Wheeler 1996). Background reading was performed during the research proposal stage and then in more depth during theory development.

Glaser and Strauss (1967) discuss how theoretical sensitivity can be lost in the early stages of data collection if the researcher commits to one specific theory and is not able to detach themself from this. In this case a theory will not emerge from the data. To avoid this happening it was important for me to recognise and ensure that the study findings were a true representation of the participants' voices (Sandelowski 1995).

3.7 Trustworthiness

Writers have proposed that qualitative and quantitative research cannot be evaluated for validity and reliability using the same strategies. Wheeler (1992) recommends that validity is not appropriate for evaluating qualitative research. Guba and Lincoln (1994; 1985) believe that establishing trustworthiness is a better option to validity and that it exists when the findings of a qualitative study represent reality. Whilst this is generally accepted, Morse et al (2002) argue that reliability and validity remain appropriate concepts for attaining rigour in qualitative research. They argue that qualitative researchers should reclaim reliability and validity by implementing verification strategies integral and self-correcting during the research process. Guba and Lincoln (1985) originally developed four terms, which are used to describe the processes, which contribute to rigour within the qualitative research process: credibility, transferability, dependability and confirmability. In later work Guba and Lincoln 1989, 1994) introduced a fifth criterion, authenticity.

Credibility relates to "how vivid and faithful the description of the phenomenon is" (Beck 1993 p264). Beck (1993) believes that credibility is achieved when the participants and readers of the study who have had the same experience are able to recognise what is being said. This is achieved by the participants and findings being described accurately (Holloway and Wheeler 1996). I asked one of the nurse participants to review sections of the findings chapter as they were written. She felt that the sections she reviewed were an accurate representation of reality. Also, during the study journey I was frequently asked to provide teaching sessions on corneal donation to palliative care health professionals. I used this opportunity to share my findings. Most participants were able to identify with the findings. Angen (2000) believes that the credibility of research relies on the skill and competence of the researcher. This is supported by Tuckett (2005) and Sandelowski (2002) who suggest that a period of apprenticeship is required before a researcher commences data collection. Before embarking on this project I had reviewed relevant literature, been involved in previous research projects involving data collection through interviews and focus groups. Also, I had supervised undergraduate and postgraduate nursing research students.

Within this study credibility was also established by describing the experience of the researcher, thus showing my involvement within the study. I was constantly aware of myself within the research process and was critical of how this would affect the findings. A study journal was used to enhance this awareness by reflecting on the research experience. Study journals contain immediate thoughts and feelings during data collection and analysis and are analytical in themselves (Tuckett 2005; Rose and Webb 1998). One entry described how moved I was by a corneal recipients description of his feelings when his sight started to return and how he spoke emotively about seeing the sea from his window for the first time in five months. The study journal became a source of data and offered the opportunity for reflection (Koch 1994).

Readers of this study want to ensure that corneal donation is accurately described by the researcher from the perspective of the stakeholders. Participants in this study guided the enquiry process. This developed as the data collection and analysis progressed. For example, in the data abstract below the nurse introduces the concept of 'shielding' and 'not causing harm'.

> "It worries me that um we may cause the patient, and of course the family to get upset. A bit of my job is to shield the patient from harm. I'm not sure if donation is ok for them." (Nurse A: 112-115)

As participants introduced new concepts these were included in the interview guide for subsequent interviews to gain further meaning.

Coding verification of two transcripts took place (Burns and Grove 2001). A colleague skilled in qualitative research independently coded the transcripts and then we met to compare findings. We reviewed her coding of the transcripts with mine and calculated the number of codes which were the same or similar. These were then calculated to form a percentage. The results showed approximately 80% agreement. As House et al (1983) recommends at least 70% inter observer agreement the coding of the transcripts were considered acceptable. Overall, the reviewer felt my coding of the data were comparable to hers.

Transferability is the second term to ensure rigour. According to Holloway and Wheeler (1996) this is about how the findings can be transferred from one group to the whole group or other groups. Within this study transferability was achieved by using theoretical sampling techniques, whereby the participants were selected to fulfil the study needs and their roles were made explicit. Thus, allowing individuals in similar situations to the participants to recognise themselves within the study findings and determine whether these reflect their own situation (Strauss and Corbin 1990; Glaser and Strauss 1967).

The potential for transferability was also achieved by including previous theories within the findings chapter. This highlighted the possible transferability of the issue to other health care situations. However, as expressed by Chiovitti and Piran (2003) "the final judgement of the transferability of the findings ultimately rests with the reader" (p433) and if they can recognise their own situation in data. During the period of this study, I was not only asked to provide training sessions to hospices who participated. There were also invites from other palliative care units and non palliative care organisations such as acute medical units, intensive care units and care homes. Even outside the palliative care setting health professionals felt they could relate to the findings, particularly regarding the use of shielding behaviour.

Dependability, which Holloway and Wheeler (1996), believe is reliant on credibility is the third term to ensure rigour. It is considered similar to validity in quantitative research (Guba and Lincoln 1994) and relates to how accurately research findings represent the social phenomena being studied (Guba and Lincoln 1994). I kept a clear audit trail so that readers can establish and understand how methodology, analytic and theoretical decisions were made. Beck (1993) describes it as reflecting the consistency of the research study. This has been recounted in many sections of this project e.g. section 3.4.6, on data analysis, provides the reader with a reflective account of how data analysis was carried out.

Confirmability according to Guba and Lincoln (1994) means that data is linked to its source so readers can identify if findings and conclusions arise directly from them. This also relates to a clear audit trail. Beck (1993) describes how auditability is achieved when the reader is able to follow an audit trail of decisions made by the researcher. Notes and reflections were kept in a study journal throughout the research process. These notes and reflections were used during data analysis and to formulate the findings and the discussion chapter (Streubert and Carpenter 1999). The study journal, for example, was helpful during data analysis as many of my thoughts and feelings following the interviews or focus groups were documented and were helpful when interpreting the meaning of data. The study journal also provided an account of my research journey and the successes and challenges that ensued. Many of these are discussed in Chapter 5.

Whilst credibility, transferability, dependability and confirmability ensured the methodological rigor of this study, Guba and Lincoln's (1994) fifth criteria, authenticity, considers issues of fair representation and the study's ontological contribution. Authenticity consists of five elements: fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity. Fairness ensures participants' acceptance throughout the study. Fairness was ensured by participants' ongoing consent and by their voices being equitably and accurately represented, whilst taking into account their social context. Ontological authenticity meant that as part of the study the participants were potentially able to gain a further understanding of their role within corneal donation. Ontological authenticity potentially took place by giving participants an opportunity to discuss what corneal donation meant to them. Educative authenticity, attempts to ensure that individuals gain an enhanced understanding of others in a particular social setting. Educative authenticity was achieved by recruiting a variety of stakeholders in corneal donotransplantation. The findings therefore may enable the reader to gain an understanding of views held by stakeholders involved in the corneal donation process. Catalytic authenticity provides participants and individuals with evidence to influence their decisions. If participants and individuals decide to change their thoughts about corneal donation within the hospice setting, 'Shielding Behaviour' would give them a theory within which to consider their actions. Finally, tactical authenticity should empower participants and other readers. This will happen if the findings of this study empower health professionals and others working within the hospice setting to discuss corneal donation as part of their practice.

3.8 Summary

This chapter has presented the aims and objectives of the study. The rationale for choosing a qualitative paradigm and grounded theory methodology was explored. How this research approach allowed a complete and rigorous explanation of the phenomena being studied is explained and justified. The methods used for sampling recruitment, data collection and analysis are described. Ethical considerations and how trustworthiness and authenticity was ensured are also explored. The following chapter will present the findings and discussion of the study.

Chapter Four:
Findings and Discussion

4.1 Introduction

In accordance with a grounded theory approach, the findings and discussion will be presented together in this chapter. Graphic representations of category development will be used to show the storyline and theory development.

Analysis of the data revealed repeated reference to the need to shield all stakeholders from physical and psychological harm. Therefore, as the most pervasive concept expressed by participants, 'Shielding Behaviour' was identified as the core category. Four other categories were identified, 'Knowing', 'Being', 'Gatekeeping' and 'Choosing' that all interrelate to support the need to shield and form the basis of the substantive theory of 'Shielding Behaviour' (Figure 4.1). 'Shielding Behaviour' is defined as:

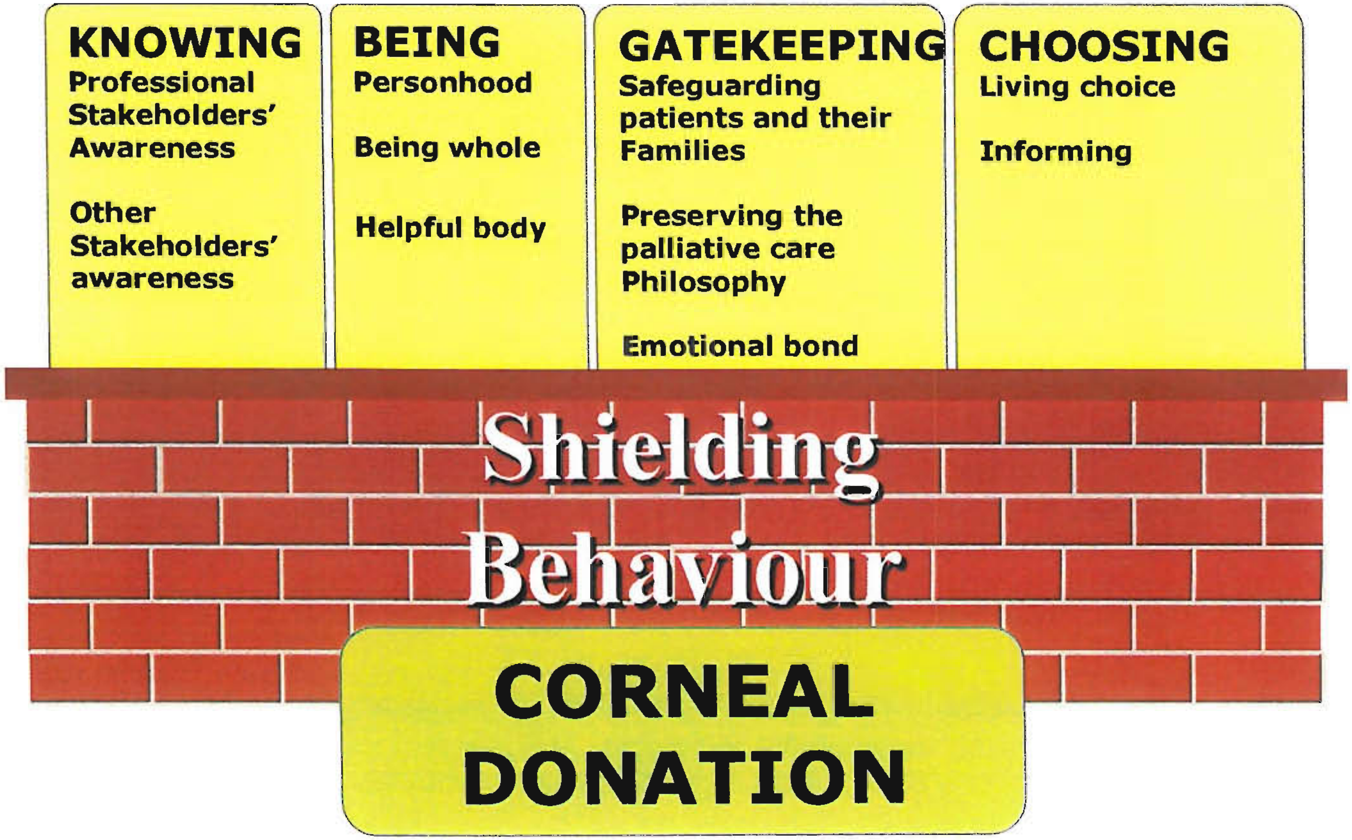
> *'the desire to shield from harm all those affected by the corneal donation process within the hospice setting.'*

The core category, 'Shielding Behaviour' will be discussed initially followed by the other four categories of 'Knowing', 'Being', 'Gatekeeping' and 'Choosing'. The categories with their sub-categories are presented in this order to provide an understandable storyline.

Exemplar quotes, integrating interviews and focus groups, will be presented as evidence to support the findings. Identification of exemplar quotes will be achieved by giving participants' codes and by providing the line numbers of the transcripts i.e. Nurse A: 133-136. Where necessary it will be made explicit if the exemplar is from a focus group (FG). Throughout the chapter single speech marks (' ') are used for emphasis and double speech marks (" ") are used to indicate speech.

Figure: 4.1.

Corneal donation in the Hospice setting: The theory of "Shielding Behaviour"



KNOWING
Professional Stakeholders' Awareness

Other Stakeholders' awareness

BEING
Personhood

Being whole

Helpful body

GATEKEEPING
Safeguarding patients and their Families

Preserving the palliative care Philosophy

Emotional bond

CHOOSING
Living choice

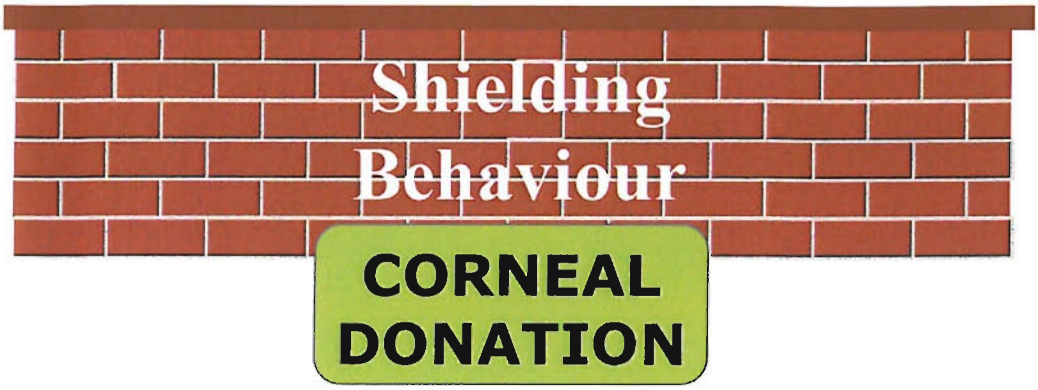
Informing

Shielding Behaviour

CORNEAL DONATION

4.2 Findings

4.2.1 Shielding Behaviour (Core Category)



The Little Oxford Dictionary (Swannell 1986) defines to shield as "person or thing serving as protection or defence": or "to protect or defend against". The need to shield individuals, not just patients but also family members, health care professionals, and the organisation (hospice) from the potential effects of the corneal donation process was raised repeatedly throughout the data. The concept of shielding was evident in terms such as "safeguard", "keep safe", "take care of", "not harm", "shield" and "protect", which were used on several occasions by all the participants. The desire to protect and shield from harm is embedded in the hospice philosophy and with the definition of palliate meaning 'to cloak' it is not surprising that participants were cautious to ensure that 'no harm' would come to patients and their families. The desire 'not to do harm' was essential for health care participants if corneal donation was to be discussed within the hospice setting. This was particularly evident when health care professionals discussed reactions, real or anticipated, to the opening of a conversation about donation. Not only the reaction of the patient or family member, but also the reaction of colleagues and themselves.

The need to protect within the hospice setting was also discussed by Copp (1996, 1999). Using a case study approach she explored the experience of patients who were facing impending death in a hospice environment. The experiences of their nurses were also examined. Copp (1999) developed a model to describe patients' and nurses' perceptions of 'readiness to die'. As a result of data analysis three major themes emerged, these were 'protecting and controlling', 'watching and waiting' and 'holding on and letting go'. The dominant theme was 'protecting and controlling'. As with this study, Copp (1999) found that both the patients and nurses needed to protect kin, patient and nurse protect each other and self. Copp (1999) also identified that the desire to protect was context related and occurred in different ways for different reasons and that the act of protecting others was not always based on altruism, there was an element of protecting self. The need to protect self was evident within this study and was related directly to corneal donation being facilitated in the hospices.

Health care participants believed they were at times over protective and therefore, prevented corneal donation from happening even though they saw donation as a potentially positive situation. The two ethical principles of non-maleficence and beneficence are well documented and are considered fundamental to health care delivery and were highlighted by a number of the participants. Non-maleficence means to do no harm, whereas beneficence is the principle of benefiting the good of the individual (Singleton and McLaren 1995). Non-maleficence and beneficence are frequently considered within the same situation and are weighed against each other. Concern about doing harm versus the possible benefits of corneal donation was identified by all the participants.

> "I often worry about how this may, um, affect the patient psychologically, but at the end of the day it is their choice to make and may actually give them a lot of joy knowing they may help someone else." (Nurse B: 264-266)

Each intervention that causes distress or harm breaches the principle of non-maleficence. However, the primary motivation to continue with corneal donation was to do good and benefit the patient with the life limiting illness, their family and the corneal recipient. Nurse B, who spoke from personal experience of agreeing to the donation of her mother's corneas after she had died in the intensive care unit, discussed how she had found the staff approach to informing her of the option to donate a negative experience, however the long term effects proved positive.

> "Although it seemed a bit negative at the time, the way it was done, in the long term it was positive because I know that's what my mum would have liked and you know she'd have been pleased to know that her death helped somebody." (Nurse B: 122-128)

The historical arbiter of what constitutes harm and benefit was the medical profession (Woods 2007). Not only did they decide what was considered harmful or beneficial, they also determined what would be done about a medical issue. This paternalistic approach to health care has long been questioned and challenged as breaching a person's rights to be autonomous, empowered and make choices for themself. Health care professionals are encouraged to acknowledge and respect an individual's autonomy. To treat an individual as autonomous permits them to exercise control over their life in terms of the choices they make (Farsides 1998). Although the health care participants acknowledged the need to provide choice, they used words such as 'difficult', 'challenging', 'often uncomfortable' and 'emotional' to describe how they felt when offering corneal donation as an option. By not having a conversation about corneal donation they voiced how they avoided the uncomfortable feelings that were evoked as they didn't feel skilled to deal with the situation. Farsides (1998) discussed how the moral and emotional demands of respecting an individual's autonomy places on each health professional the responsibility to acquire skills required to respect and promote the autonomy of their patients.

The discord which was created by health care professionals, between shielding the patient, their family member, themselves, and the desire to respect and meet the patient's wishes regarding donation, supports some of the findings of Kent's (2004) work. Although Kent (2004) only explored the behaviour of nurses who worked in acute clinical areas and not the hospice setting, Nurse A and B expressed behaviour which support Kent's (2004) concept of 'protective behaviour'. Including, the fear that family members would not cope with a discussion and also concerns about negative reactions of family members and colleagues to discussing donation. This study builds on Kent's (2004) work by exploring the views and feelings of multiple stakeholders within the hospice setting regarding corneal donation.

Health care participants often hesitated to directly inform patients and their families about donation as they were concerned that the reaction would be one of disapproval or anger, even among colleagues. Nurse B spoke about how when she mentioned the possibility of informing patients or families about donation she felt at times that some of her colleagues' reactions were unsupportive and they were judging her clinical practice. She had felt so uncomfortable with their reaction that she stopped broaching the subject with families and patients. This overriding belief in a negative reaction outweighed the perceived benefit of the donation process and appeared to lead to a general culture of non-disclosure about the option of donation.

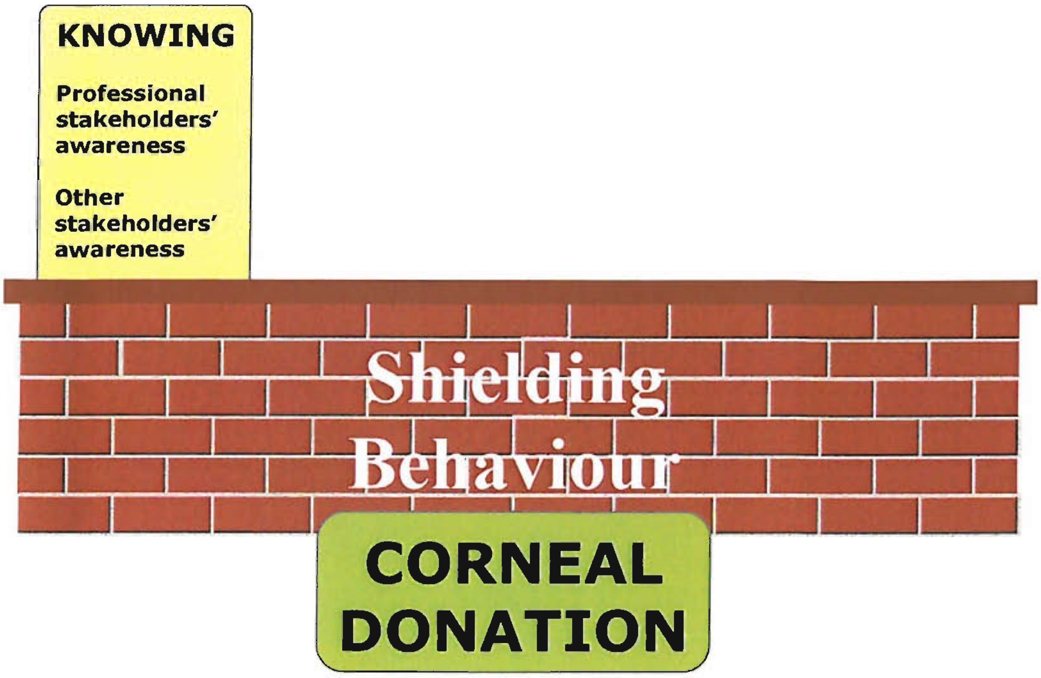
In situations where individuals were informed about the option of donation, health care participants appeared to employ a subconscious evaluation of the possible reactions they may encounter. If it was deemed that the risk of a negative or angry reaction was outweighed by a possible positive response then they considered progressing with a discussion with patients and families. All the nurse and doctor participants expressed feelings of increased anxiety and fear of an anger response when they considered informing patients and their families about corneal donation. This not only supports Kent's (2004) findings that nurses have a fear of a negative reaction to a discussion, but also that doctors have similar fears. Both doctor participants believed this was a key reason why corneal donation was rarely discussed. Displays of anger are emotions that health care professionals find challenging and emotionally difficult. Smith and Hart (1994) discuss how nurses avoid situations which may provoke anger as it made them feel vulnerable and caused them to blame themselves for provoking what was considered a negative emotional response. Health care participants wanted reassurance that they were doing what the patient, or their families, wanted by picking up cues during conversations and by adopting strategies to minimise the risk of a negative response.

> "I would only consider discussing corneas if they indicated during a chat that they would want it." (Nurse A: 242-244)

Although participants discussed concerns that a discussion about corneal donation may cause a negative emotional response by patients or families, none of the participants could give an example where this had occurred. It appears that an anger reaction to a discussion about corneal donation could be a perceived rather than actual response.

Strategies employed to shield individuals from a donation discussion will be explored throughout subsequent categories. The following four categories are put forward as reasons why there was this over-arching dilemma between doing no harm versus potential good.

4.2.2 Knowing



The category 'Knowing' relates to stakeholders' awareness of corneal donation in general and more specifically within the hospice setting. Two sub-categories support this category. First, the health care 'Professional stakeholders' awareness', and how this is influenced by factors internal and external to the hospice setting. Second, the 'Other stakeholders' awareness' and how this is influenced by health care professionals, the media, publicity, previous knowledge, attitudes and experiences. Other stakeholders included all participants (chaplains, bereavement counsellors, patients, bereaved family members and corneal recipients) except health care professionals who were discussed in the previous section.

'Knowing' addresses how participants became aware that patients who die in the hospice setting can potentially donate corneas, and their possible reactions to the increased awareness. Variations in knowledge about the donotransplantation process became very apparent during data analysis and appeared to influence participants' behaviours.

4.2.2.1 Professional stakeholders' awareness

There were several phrases and words used within the data that represented health care participants having limited knowledge about corneal donation as an option for patients with a life limiting illness. These included "don't understand", "may be", "uncertain", "hadn't really realised" and "I hadn't thought of that". Poor knowledge about the opportunity for patients to donate tissue outside the intensive care unit has been previously cited (Wells and Sque 2002; Kent and Owen 1995) and is confirmed by a dearth of literature on the issue outside this clinical area. Gore et al (1992) even found that the donation of tissue was rarely considered by health care professionals working in the intensive care setting as their focus was on the donation of organs. If the intensive care setting consider tissue donation as low priority compared to organ donation (Kent and Owen 1995), it could send mixed messages when proposing strategies to influence participation and increase the donation of tissue within other clinical settings. Concern that tissue donation was of less priority to organ donation was expressed by the donotransplant coordinator participants, the ophthalmic surgeon and the eye bank coordinator and linked to corneal donation being life enhancing rather than life saving.

> "I think as transplant coordinators we put more effort into organ donation, both with training and supporting families. I think they're all extremely important, but organ donation at the end of the day saves lives."
> (Donotransplant Coordinator B: 157-161)

Although the health care participants had limited knowledge about corneal donation they were aware of it being an option for patients within the hospice setting. However, the extent and accuracy of that knowledge varied. They said they had become aware of corneal donation as an option for palliative care patients through working in hospices where patients and families were informed about donation or via informal discussions with colleagues. Staff training and information about donation had been provided on an informal 'ad hoc' basis, "in-house chats", "over lunch", "learnt from others" and "we had a sister who was interested so she told us about it". Nurse A, had attended a teaching session by the eye bank coordinator. However, she did not feel it gave her the knowledge and skills, principally "what to say", to feel confident to discuss the issue with patients or families.

All health care participants discussed the importance of team dynamics and strong nursing leadership within the hospice if corneal donation was going to be discussed.

> "People say at the time, oh it's great but you come back to the reality of it, it's difficult to put into place and, or you get people back at the hospice going yuck we're not doing that, so the dynamics of the team and particularly the ward sister play a major part." (Nurse B: 427-432).

Increased motivation and performance is linked closely with team cohesiveness (Daft 1999). Another factor is shared missions and goals. When team members agree on goals and visions they will be more cohesive and as a consequence more successful and committed (Daft 1999). Leadership of the team was expressed by participants as an important element and influential to practice and levels of performance. A designated person who would act as a leader and role model was considered essential for discussion about donation to become part of health care professionals' practice.

> "Depends too on I think on who's in charge. So if you've got somebody that's in charge and that's very enthusiastic, that does help."
> (Eye Bank Coordinator: 356-358)

> "I always knew there was corneal donation, but it was only when one of the sisters on the ward had a real interest in it that we started to take it forward a step. We all became more involved and understood it a little bit better about what was involved." (Nurse A: 24-28)

Successful teams begin with confident and effective team leaders. Walton (1997) discussed that leaders can apply their insight and training to improve performance in others and by being a role model and supporting colleagues, the motivation for change can be achieved.

Although, there was apparent knowledge that patients with cancer could be potential donors there was less knowledge around co-morbidities and how this influenced donor acceptance. Also health care participants expressed inaccuracies about the donation process. Phrases such as "they (eyes) have to be removed within 12 hours", "it has to be done in an operating theatre" and "we don't have the equipment at the hospice" were used. Knowledge about donor eligibility and the donation process has been shown to play an important role in whether health care professionals discuss donation (Sque et al 2000; Kent 1995; Gore et al 1992). The importance of knowledge was identified by Sque et al (2000) as influencing nurses' confidence towards discussing donation. Siminoff et al (1996) also showed that accurate knowledge about donation could lead to a 2.5 fold increase in the likelihood of families being informed about the choice. All health care participants perceived they had insufficient knowledge about donation and initiating conversations with patients and families within the hospice setting.

4.2.2.2 Other stakeholders' awareness

If the health care participants perceived they had insufficient knowledge about corneal donation it is not surprising that the other stakeholders appeared to have even less understanding of corneal donation within the hospice setting. All the other stakeholder participants had heard of corneal donation through the media, publicity or previous experience. However, none made a direct link to palliative care patients and their families having the opportunity to make a choice. Reason participants believed patients in hospices were unable to donate corneas included "no ventilators", "no operating theatre", the impression of medical technology, "drips and monitors", that individuals think about when donation is mentioned. However, the most common reason was linked to a cancer diagnosis. All the patient, bereaved family member and corneal recipient participants expressed 'surprise' that a cancer diagnosis did not automatically exclude the opportunity to be a donor.

> "I thought that people with cancer probably nobody would want any bits of their body for donation. Well if so many parts of their body are diseased when they've got the spread of cancer, I just assumed there wouldn't be anything that was any good."(Patient A: 33-37)

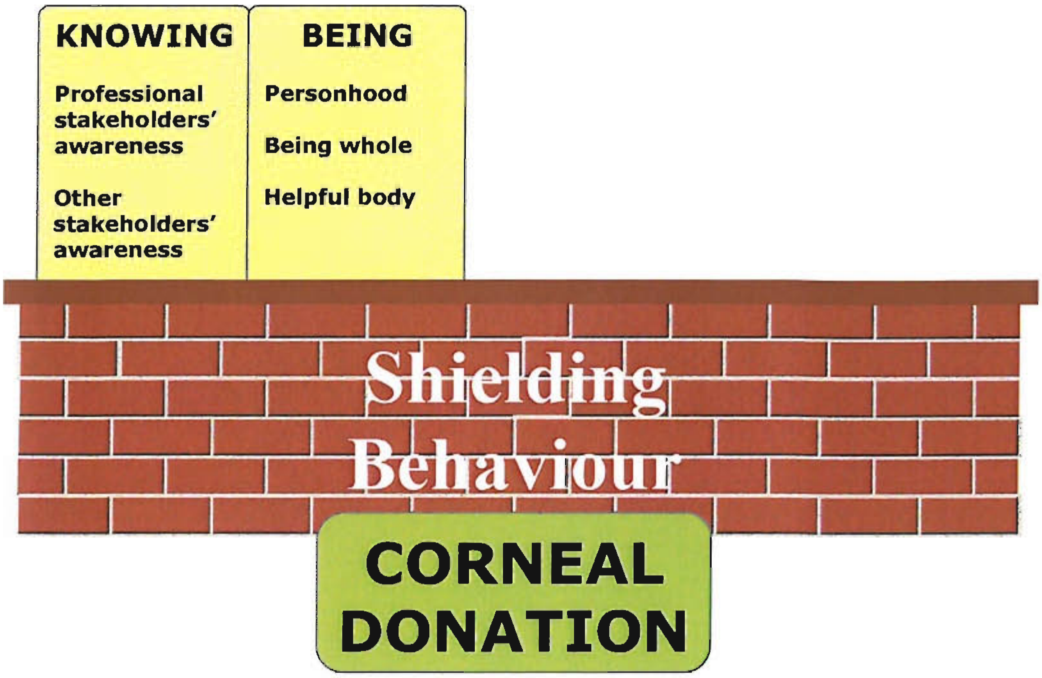
This assumption is supported by previous studies on tissue donation in palliative care (Hughes 2005; Carey and Forbes 2003; Wells 2000). Carey and Forbes (2003) found that 8 out of 10 family members who had consented to donation of corneas of a family member, who had died of cancer, were 'shocked' that they were able to be donors regardless of their disease. This was also the case with hospice patients who believed they may 'contaminate' the recipients (Hughes 2005). One patient participant in this study said she had seen a leaflet about corneal donation at the hospice but didn't pick it up as she assumed she would "be no good". Bereaved Family Member A, who had provided a 'lack of objection' for his wife's corneas to be donated, said he was initially shocked when a nurse mentioned that his wife could be a donor. He and his wife carried donor cards but he had not considered it a possibility as she was 82 years old and had cancer. As with the health care participants there appeared to be a lack of awareness of the eligibility criteria to be a corneal donor and in particular a general assumption that a diagnosis of cancer excluded donation.

The understanding of corneal recipients was also considered and their awareness of the donation criteria and process. The fear of contamination by palliative care patients in Hughes (2005) work was not a concern voiced by the corneal recipient participants in this study. Both were unaware that their corneas may have been donated by someone who had died of cancer, and neither had concerns about this, as they put "trust in the ophthalmic surgeon's decisions".

> "I think that anybody concerned should have confidence, be confident in their, in the people, doctors and so on that are treating them."
> (Recipient B: 217-219)

Corneal Recipient A remembered the surgeon informing him that the cornea had been donated from an individual who had died. Recipient B could not recollect the surgeon telling him this but made the assumption himself. Both corneal recipients, who had received their corneal transplants within the previous year, said they had not given much thought to the donors since their transplant, using phrases such as "it's not like the heart or lungs" and "it's only a cornea". The fact that it was a corneal transplant appeared to evoke less interest in the donor than in the case of organ transplantation. A different response to organ recipients, who may invest a lot of thought and energy in thinking about their donor (Sque 2000; Vajentic 1997; Lewino et al 1996).

4.2.3 Being



The category 'Being' means the nature or existence of a person. It consists of three themes: 'Personhood', 'Being whole', and 'Helpful body'. 'Personhood' refers to the need to maintain the potential donor's identity if corneal donation takes place. 'Being whole' relates to people's interpretations of death, the afterlife and the significance of the eyes to individuals. 'Helpful Body' pertains to how individuals perceive the meaning and purpose of corneal donation for dying patients and their families.

4.2.3.1 Personhood

Personhood has been described as one's identity as a social person, influenced by socialisation or cultural influences (Giddens 1998; Armstrong and Fitzgerald 1996). There has been ongoing discussion and argument amongst researchers about what constitutes a person. Taylor (1985) believed that personhood consists of two separate components: an identity and a self. The self is one's inner subjective being. Whereas, identity is external and is dictated by cultural meanings and community memberships (Taylor 1985). Giddens (1991) suggests that the body is a medium through which the self is expressed, fashioned and shaped.

All participants discussed protecting patients' dignity at the end of life. More specifically the concept of protecting their self or personhood and whether this could or could not be maintained if they became a corneal donor. There was a fear by participants that by the patient donating their corneas they could risk "violating" their personhood. This appeared to be linked to whether the patient was involved in the decision making process. If the patient was involved in the decision making process health care participants believed they were respecting the patient's wishes as a person and therefore maintaining their personhood. Whereas, if a lack of objection was obtained from a family member, health care participants appeared to have more difficulty conceptualising whether it was the right course of action for the patient. Doctor B spoke about how she felt "more comfortable" when she knew patient's wishes and how she was then respecting them as a person.

How an individual's personhood is affected by a serious illness has been explored over several years (Kabel and Roberts 2003; Lawton 2000; Copp 1999; Murphy 1990). Murphy (1990) suggests that when someone is faced with a serious illness they are often faced with physical, emotional and social losses, which can challenge their personhood. When participants in this study discussed cancer, terms such as "ravaged with illness", "fighting against their bodies" and "useless body" were used to describe the effects of the disease.

> "I suspect that their bodies are so ravaged with illness that there's nothing that can be useful. If they can I'm not sure they would want too. It might be too upsetting."(Chaplain B: 251-252)

These are not images that participants said they associated with the donation of organs and tissue for transplantation. The concern about the patient's body being "ravaged with illness" and the effects this has on families and patients is not a new phenomena (Lawton 2000; Copp 1999). Lawton (2000) describes how hospice patients in her study reached a stage in their illness where they felt they were being "taken over" by their diseased body (p77). Both patient participants used the term "useless" to describe how they felt about their bodies. When they realised they could be potential corneal donors they became animated. Patient A appeared emotional at the thought of her body being potentially useful.

> "It is so good to know that I'm a not useless and even though the body is becoming more crappy, I can still do something for someone else. That's a good feeling."(Patient A: 325-327)

What this could suggest is that personhood is principally tied to bodily capacity and that when patients loose bodily ability and independence, which can happen when people are dying, there is a loss of self. However, there were indications within the data, as shown by Patient A, that corneal donation could enable the patient to maintain their personhood.

One of the founding principles of the hospice movement is to enable patients to live with their illness. In essence supporting the individual's personhood. This principle was challenged by Lawton (2000) who suggested that dying patients were often reduced to being considered 'just a body'. Lawton believes that if patients are perceived to be a body and not a person when they are dying, then the patient will experience a loss of personhood. However, the findings were restricted to data collected from one UK hospice and therefore the findings may not be transferable to other hospice settings.

The idea that health care professionals don't just consider a dying patient as a 'body' but also as a 'person' is suggested by Copp (1999), who explored patients' and their nurses' experience of 'facing impending death'. Copp (1999) suggested that when a patient's death became imminent, nurses were able to separate the person's body from their personal self, a 'body-person split'. Therefore, considering the body as a separate entity to the person. Copp (1999, 1996) proposes that this body-person split was achieved by hospice staff particularly when they had known and cared for the patient prior to them loosing consciousness.

All the health care participants in this study appeared unable to separate the body from the person when caring for dying patients. They discussed the importance of the care they gave to patients at the end of life using terms such as "it's the final care you can give to a person", "they are someone's loved one" and "I care for them the way I would want my family members to be cared for". The use of the words "person", "loved one" and "family member", challenges the concept of staff considering the dying patient as only a body or being able to separate the person from the body. The fact that health care participants appeared unable to separate the patients' body from the person when considering corneal donation could be considered a contributing factor to protecting them from the donation process; therefore, supporting their personhood.

A more recent study by Kabel and Roberts (2003) also challenges Lawton's (2000) findings. The analysis of interviews of 30 hospice staff explaining the maintenance of personhood at the end-of-life, showed that when a patient is unconscious the person remained intact whilst the body disintegrates. Health care participants suggested that knowing the patient and their family members made it much easier to provide care for the patient and support the family when the patient was dying or had died. Being able to provide ongoing care the way the patient found most comfortable and "knowing what they liked" was expressed as important. Having experience of how the family members responded to situations appeared to give health care professionals insight into how they might respond to stressful situations. This knowledge was important to health care participants when they considered discussing corneal donation.

The perception of the bereaved family members in this study was that they believed their loved ones' personhood was maintained whilst at the hospice and that the attention provided by the staff was "very caring", and "humane". Staff treating their ill family members like "human beings" appeared important to them. As Bereaved Family Member B, whose wife was transferred to the hospice, from a general hospital, five days before she died expressed:

> "She was treated like a real human being in the hospice right up to when she died. Not like that other place where they treated her like a piece of meat."
> (Bereaved Family Member B: 112-115)

His apparent anger at the previous care she had received was evident and that respecting and treating his wife as a "human being" was important to him. When asked to talk about how the hospice staff treated her like a "human being", he spoke about how staff were "talking to her even when she wasn't able to respond", "keeping her clean" and "putting on her favorite perfume". Even when she had died and he had given a lack of objection for her corneas to be donated he spoke about how they still treated her with respect at all times. The perception of both bereaved family members in this study was that the staff treated their loved one as the person they were even after they had died and throughout the corneal donation process.

4.2.3.2 Being whole

The desire for the body to remain whole after death was raised by a number of participants as a reason why the subject of donation may not be broached within a hospice setting. Although not a belief of all the participants it was given as a possible explanation for the low commitment to corneal donation. Two participants (Nurse A and Chaplain A) expressed a personal desire to be whole after their death. Nurse A, believed she may need her whole body in the "next world" and Chaplain A, said "it just seemed right to be whole". Although both felt strongly about their beliefs they also voiced that their viewpoints and explanations were irrational. Nurse A, stating she had no religious reason for this belief, "I'm edging my bets". Whilst Chaplain A, believed the odds were that he would die by being "run over" or involved in a car accident which may leave him "mutilated" and "not whole".

The desire to be buried whole has been shown to be a considerable barrier to the donation process (Verble and Worth 1999; Pearson et al 1995; Kent and Owen 1995). Pearson et al (1995) found in a survey of 69 families of brain-dead patients that eight of the 27 families who did not support organ donation believed that the body "should be left in peace". Whilst Kent and Owen (1995) in a study of nurses' attitudes to corneal and organ donation found that 25% of nurses would not donate their eyes due to fear of disfigurement. Verble and Worth (1999) reviewed the literature pertaining to the fear of mutilation in the donation process. These fears of mutilation were seen as an animal fear that emerged and persisted because it provided a biological advantage to our ancestors if they were going to survive a primitive environment. They referred to the fear of mutilation as 'animal learning' and suggest that it is fixed firmly in our genetic past as primates and is difficult to eradicate (Verble and Worth 1999).

Another possible reason for people's fear about mutilation of the body was explored by Richardson (2000), whose discussion pertained to the public, historically viewing dissection as a punishment, 'fate worse that death'. Only those who had committed the worse crimes were suitable for dissection and therefore may explain some of the fear and concerns that surround present day organ and tissue donation. Particularly fears that dissection and therefore, the donation process may damage the soul and prevent the possibility of resurrection.

A number of participants stated their belief that individuals may have a desire for their body to remain whole after death and therefore, not donate their eyes. Reasons included: "needing to see in the next life", the fear that the chance of resurrection after death would be hindered if they donated organs or tissue, and that their souls would be damaged, were genuine concerns for participants. Although, Chaplain A believed there was no theological evidence to support the need to be physically intact after death, he did discuss how this belief goes back for centuries. He described an incident where a 17th century body was exhumed in a parish where he served, and how it is a good example of the need for the body to remain whole after death.

> "They found a woman who had obviously had gangrene, in that, her left arm was missing and a section of her left arm was amputated sort of like two inches below her shoulder and then a section of her arm was missing. Then her hand was in the coffin with er, in a glass bottle. So they'd obviously gathered together all the bits you know, and they had this idea of you know, at the resurrection you have to be whole." (Chaplain A: 315-322)

Four participants talked about how not being whole after death may have implications for the afterlife and soul. Although this was not expressed by the patients and bereaved family members it was a concern for other participants in the study. They spoke about how these could be some of the reasons individuals would choose not to donate. Sanz-Ortiz et al (2005) believed that whatever we believe about the afterlife, what is inevitable and beyond question is that we will lose this life. Humans unable to contemplate the idea of an inevitable end are believed by Sanz-Ortiz et al (2005) to invent safety nets for such torment: the belief in an afterlife and immortality. For example, Nurse A, expressed that she wanted her body to remain whole after death as she was "edging her bets" of an afterlife where being whole was necessary. Chaplain B on the other needed to be whole for there to be any possibility of an afterlife.

> "For Anglicans there's nothing against it because we believe that it's er the you know the resurrection of the body has nothing to do with God managing to find all the bits. And anyway if God can create out of nothing, I'm sure he can re-create out of nothing." (Chaplain B: 301-305)

He suggested that such beliefs were contradictory to Christian theology. He became animated and quite annoyed that people believed you need to be whole after death. He was concerned that these ideas were "contagious" and were spread by people to protect themselves from the unknown. However, the reality was it caused "fear" and "anxiety".

Another saying which was frequently raised by participants was that "eyes are the windows to the soul". Again where this phrase originates from is difficult to determine. There has been some debate on the phrase's origin ranging from it being an old English or Arab proverb, to a statement in the Bible, Mark 7: 20-23, which reads, "The eyes are likened to the windows of the heart". The biblical reading makes no reference to the soul and therefore could be interpreted differently to the heart. The three chaplaincy ministers who were interviewed were unable to explain its origin. Chaplain C, described it as:

> "A convenient little piece of clichéd metaphor, um, it actually is not true." (Chaplain C (FG2): 212-213)

FG2, which consisted of bereavement counsellors, social workers and chaplaincy team members spent a lot of time debating what 'eyes are the windows to the soul' meant to them and how the eyes and the soul were linked.

> "My understanding of the eyes are the window of the soul, somehow revealing what's going on, you know, as a person's inner eye expressing it through the eyes, but not in the sense of this some kind of metaphysical connections between the eyes and a person's soul. I suppose people could take it that way, but I don't understand it." (Chaplain)
>
> "I always think that the soul has departed the body and therefore the Eyes no longer need to be that window, but again." (Bereavement Counsellor Leader)
>
> "These cliché's become seen as truth, they're not in the Bible, either of those things. Just as charity begins at home, it's a good excuse for not doing anything er, I you know, but these things become received wisdom." (Chaplain Volunteer A)
>
> "I've actually heard it but I have no idea where, and I may have read it because I can't put a person, a figure of a person, I can't think of a person saying it, so I may have read it but I've certainly heard it, the eyes are the window of the soul. But again it's a cliché which means nothing." (Bereavement Counsellor A)
>
> "But its got meaning?" (Chaplain) (FG2: 441-485)

During this focus group discussion there appeared to be two main contrasting positions set up and debated. At times, challenging each other's belief system and religious stance. First that there was meaning to 'the eyes being the windows to the soul' and second that there was not. What this led me to deduce was that although there seemed no clear religious meaning linked to 'the eyes being the windows to the soul', it appeared to evoke a lot of emotion and has personal meaning to individuals. Verble and Worth (1999) believe that mystical modes of thought that are culturally ancient and impervious to the rules of logical meaning and subjective reality are not amenable to public education efforts. Therefore, health care professionals need to be sensitive and non confrontational to individual views and respect their beliefs.

As the eyes are the tissue most commonly donated by patients in hospices it provoked a lot of other discussion besides 'the windows to the soul' debate. Eyes appear to go beyond the physicality of donating tissue or organs. They evoke meaning about the deceased person when they were alive. Eyes being external to the body, unlike internal organs such as kidneys and livers, participants believed would cause patients and family members to have more conflict when making a decision about donation.

> "Because eyes are part of what the person is and you get relatives talking about how they love their husband and wife, and they do say they have got lovely eyes or can you look after their eyes. They say their eyes are this or their eyes are that. There is a lot connected with it." (Nurse A: 44-48).
>
> "Um, it's a sort of focus of a person isn't it, looking into the eyes."
> (Nurse B: 142)

Eyes and their meaning to people are very emotive and sensitive and is often the tissue people are unwilling to donate (Sanner 2001; Morgan 1999; Skowronski 1997; Kent and Owen 1995). Morgan (1999) found through interviews with bereaved family members of organ donors that eyes were very symbolic of the person who had died. Particularly surrounding the importance of appearance and sight. Four participants in this study suggested that eyes were an integral part of attraction between two people and a significant part of the face and therefore, an integral part of that person.

The discourse surrounding sight is far reaching and goes beyond the mere function of seeing (Morgan 1999). Elias (1987) discusses how the smile is an important signaling mechanism between humans. Key to the smile is not the muscle changes that take place but the expression in the eyes that complete the picture. Eyes are therefore an important medium during communication and attraction between two human beings.

> "Her eyes were so beautiful; it was the thing I remember about the first time we met." (Bereaved Family Member B: 224-225)

Some American corneal retrieval teams are perfecting techniques where only the corneas are removed rather than the whole eye after death (Lane et al 1994). Currently there is no evidence to support whether these techniques will change people's views about corneal donation. Although, there is mounting evidence to support public difficulties in donating corneas, the patients and bereaved family members in this study discussed that they felt donation of the corneas was less intrusive than the donation of organs.

4.2.3.3 Helpful body

All the participants expressed how the act of corneal donotransplantation could have positive effects for not only bereaved family members and health care professionals, but also the patients who are dying. They described corneal donation as "a gift" to give "help", "be of use", "give back" and "give sight" to someone else. There was a lot of discussion around corneal donation providing a "positive outcome" for patients and family members and to give them a sense of "continuity" or "link carried forward". The idea of continuity was raised on several occasions by participants.

> "It's the knowledge that their death, the life helps somebody else, that you know somebody somewhere is going on with seeing that they couldn't do before." (Nurse B: 361-365)

All participants discussed how agreeing to donate corneas after death could provide "meaning" and "purpose" to a patient or family member. Despite families being placed in the position of immense stress and sadness at the loss of a family member, evidence suggests that donation can give positive meaning to their loss (Sque et al 2006; Carey and Forbes 2003; Sque and Payne 1996; Pelletier 1992). Pelletier (1992) found that the majority of families were grateful for being given the opportunity to consider donation and believed donation had given positive meaning to their loss, causing them no additional stress. This is also supported by Carey and Forbes (2003) that all the bereaved family members were glad that they had agreed to corneal donation and few believed it directly affected their bereavement. Eight out of their 12 participants said they would have been distressed if they had not been given the option to donate.

The Ophthalmic Surgeon discussed how he saw the gift of sight as "phenomenal", particularly when the outcome of one individual donating their corneas can give two people sight. As he described, "it gives them their lives back". Examples of how the corneal transplants had changed recipients' lives were explored. Corneal Recipient A, who had received a corneal transplant eight months before the interview and had recently received a second transplant to his other eye, spoke about becoming suddenly blind from an infection. He lived in a flat with a sea view.

> "I only brought this flat for the view then one day I woke up and couldn't see it anymore. The thought of never seeing the waves and the changing colours was just devastating *(became tearful)* I get upset remembering it."
> (Corneal Recipient A: 123-126)

He received a corneal transplant three months after he lost his vision. During that time he described "living as a blind man" and how he was dependent on others to do "everything", rarely leaving his flat. On receiving the first corneal transplant he told with excitement about the changes it made to his quality of life.

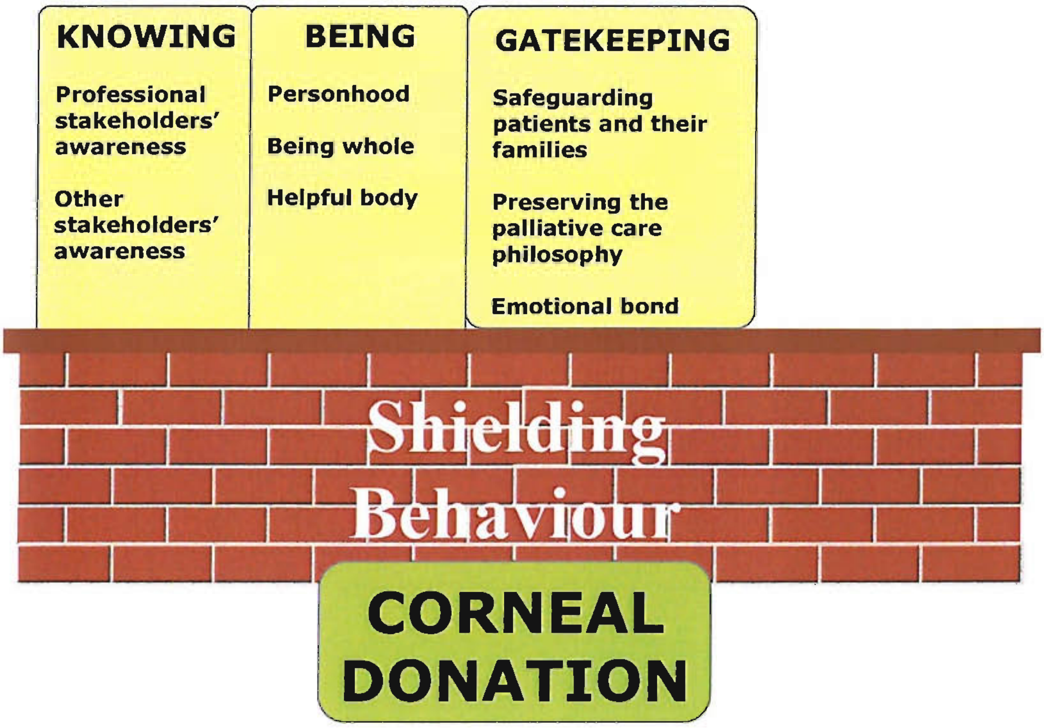
> "I went from a man who was dependent on others back to my old self. I've even got a girlfriend now. Not bad for an 84 year old."
> (Corneal Recipient A: 276-278)

He spoke about his sight being better after the corneal transplant than before he lost his sight. This was also expressed by Corneal Recipient B.

> "I found that colours were more brilliant. I mean greens and yellows and reds and blues, they just hit me. I went to my checkup with Mr...(Surgeon) and said I am seeing things more clearly. He said I probably had a pigment in my own lens which altered colour but now that has changed."
> (Corneal Recipient B: 311-316)

All health care participants appeared to have limited knowledge of how corneal donation could potentially change a recipient's life. Although this study had a small sample and may not be transferable, for the participants who were involved there was a general feeling that having knowledge or meeting a corneal recipient could influence and motivate them to consider discussing corneal donation as part of their clinical practice. By health care participants suggesting that their motivation to discuss donation could be influenced by knowing the impact of a corneal transplant on a recipient's life, appears to suggest that the already discussed balance between doing no harm and potential benefit could be altered. It appears that if health care professionals have an understanding of the wider implications of the donotransplantation process rather than restricting their knowledge to what happens within the hospice setting there could be shift in attitude and moves towards discussing corneal donation as part of their practice.

4.2.4 Gatekeeping



The category 'Gatekeeping' refers to strategies that were developed by individuals and organisations to protect patients and their families, the hospice philosophy and the relationships that were formed i.e. 'emotional bond'. The formation of a relationship between health care professionals, patients and family members appeared key to successful approaches to corneal donation. Part of this relationship involved good communication and sharing of information. Good communication was considered by participants an essential skill for health care professionals and fundamental to the hospice philosophy. Regardless of this health care professionals were reluctant to share information relating to corneal donation. In some instances there was a disregard for the subject with staff either "not thinking about it" or feeling they have "too many other things to think about". Health care participants who did think about donation as part of the care they provided discussed how they would first identify the recipient of the information and then make a decision whether they deemed it appropriate to discuss the information. They took into account what they knew about the patient or family, their emotional status and how they believed they would react to the information. Health care participants provided a rationale for why they did not discuss donation; the principle reason being the protection of the patient and family member from unnecessary harm or distress. This category explores the strategies health care professionals used, and whether these were appropriate strategies to initiate when considering corneal donation.

4.2.4.1 Safeguarding patients and their families

All the health care participants displayed evidence of paternalistic behaviour towards the patients and families when considering whether corneal donation should be discussed as an option. The responses of the health care participants appeared to indicate that they were the individuals who decided whether patients and families were informed about the option of corneal donation and many gave justification for their actions. Dworkin (1972 p131) describes paternalism as:

> *".....interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person coerced."*

Bassford (1982) states, that paternalism is motivated by what is perceived to be good for the person who is the object of the act. Bartter (2002) suggests that nurses and doctors justify their paternalistic actions by frequently referring to the doctrine of the 'nurse/doctor knows best'.

> "Sometimes I find that events overtake them and you know, they aren't expecting it to happen, it's all happened too quickly or it's all been too traumatic and they can't think about it. So people are so preoccupied or worn out, they've got other things on their minds. Then I think it shouldn't be mentioned." (Nurse A: 206-210)

Health care participants during the interviews and focus groups were contradictory when talking about why they did not discuss donation. However, they said they felt guilty as they believed part of their role was to "share information with patients and families" and "give them choices". Nurse A, who expressed reasons not to discuss donation with patients and families, also expressed personal conflict why she found it difficult to discuss, feeling she was being judgemental in her approach.

> "Yes they probably have been through enough, but, you still don't know what they were like previously, because you don't always get to know about the person beforehand and things and I think it is how you interpret things and they have been through a lot, but I think that's us judging whether they're capable of knowing or not. We shouldn't really do that."
> (Nurse A: 305-311)

If health care professionals are not going to discuss corneal donation with patients and families it appears that they need to be clear that the discussion about donation has sufficient moral weight to justify not broaching the subject. Despite Nurse A's belief that the decision not to discuss donation is in the patients' and families' best interest, decisions that override the patient's autonomy and ability to make choices are considered paternalistic (Edwards 1996): a concept considered taboo in UK health care (Jensen and Mooney 1990). All participants were concerned that to discuss corneal donation, the subject of patients' dying had to be broached. There was a view that not all patients or families wanted to talk about their death and therefore a conversation about corneal donation would be distressing. It was felt that health care professionals should use their communication skills to pick up cues to decide when to discuss corneal donation. This approach is supported by Hughes (2005), who on interviewing day hospice patients about donation found that they all felt it was important to be informed about donation. However, they also voiced concerns that some patients could find discussing donation difficult as it forces them to face the finality of their life. Hughes (2005) suggested that staff who knew the patients should have the ability to decide when to discuss donation.

All health care participants talked about how they would find it easier and more appropriate to talk about donation if the patient and family openly discussed death and dying with them.

> "It's the patient. How they accept their illness, how openly they discuss things. For example, they've said that I'm thinking of making a will because I know I haven't got long. If we're talking about deterioration and preparation for death then it might be the right time to discuss donation."
> (Doctor A: 183-187)

This approach is supported by Seale et al (1997), developed from the earlier work of Glaser and Strauss (1966), who describe open awareness as when both the dying person and the respondent know that the person is dying. Open awareness was found to increase health care professionals' willingness to disclose information and offer choices about issues concerning the patient's death. Seale et al (1997) concludes that awareness of dying enables life planning and offers a degree of control over the manner and timing of death.

Although all the participants believed that patients and their families should be informed about donation, comments suggest there could be concern about its perceived emotive context. The perception that a corneal donation discussion would be emotive appeared to stem from the fact that the conversation would evoke thoughts of death. Moloney and Walker (2002) contest these findings as their research found that whilst donation provoked thoughts of death, participants were able to abstract themselves from the reality of donation situations and discussion was not, therefore emotive. However, the participants of Moloney and Walker's (2002) study were the general public and not individuals facing their own mortality and impending death. This would lead me to deduce that individuals may alter their reaction to a discussion about donation when living with a life limiting illness. The patient participants in this study appeared to find it difficult to separate donation and death i.e. distancing themselves from their own mortality. Talking about donation seemed to prompt a shift towards considering their future, which both patient participants found uncomfortable.

> "I try to live each day without consciously thinking about the future. I'm not stupid, I know I'm going to die but I try not to think about it too much." (Patient B: 98-100)

These findings are supported by Hughes (2005) and Lawton (2000). Lawton (2000) discusses how palliative care patients rarely discuss the future and consciously avoid situations that will bring it into focus. She found that whilst healthy people's time is directed to the future, this is inherently problematic for patients with a life limiting illness who strive to construct a life within the "present rather than future orientated temporal framework" (p48). Although both patient participants in this study appeared to use strategies to avoid thinking about the future they also spoke eloquently and made it clear that they would still want to be informed about the donation option, even though Patient B did not want to donate her own corneas.

> "It might be an uncomfortable subject to talk about it but it is so important to know you can do it (corneal donation). Lots of things I talk about with the nurses and doctors cause me to feel upset. That doesn't mean it's wrong to tell me." (Patient B: 108-112)

All health care participants said that ensuring corneal donation did not cause further distress for family members during their bereavement was essential. Not knowing the answer to this was given as a reason not to discuss donation.

> "Until we know whether it causes distress for relatives in their bereavement, I am not happy to discuss it." (Nurse A: 334-335)

The bereaved family members who were interviewed during this study did not feel donation had caused their grief to be any worse. Bereaved Family Member A who had been married for 60 years spoke about how nothing could cause "loosing his wife" to be any worse. As he spoke about his wife he spent a lot of time crying and reminiscing about their life together and how he now felt "empty" without her. The same sentiment was voiced by the Bereaved Family Member B. These findings are supported by Carey and Forbes (2003) who also found that 90% of bereaved families who had agreed to donation within the hospice did not feel that corneal donation had affected their bereavement in a negative way. The experience and benefits for bereaved family members of most organ donations is well documented. Sque et al (2003) showed that in the intensive care situation families who were comfortable with their decision about donation may be less likely to have a complicated bereavement with unresolved grief reactions. Bereavement counselling was offered by hospices for all bereaved family members. However, neither of the bereaved family member participants accepted, which is supported by the findings of Carey and Forbes (2003).

Another reason which appeared to influence health care participant's decision to discuss corneal donation was that they were concerned it could "insult" the patients' religious beliefs. There was a general belief that many religions object to donation. All health care participants made inaccurate assumptions about religious beliefs and donation, or admitted they did not know what they were; so avoided a discussion.

> "We need to consider many religions don't agree with donation. I think the Jewish and Eastern religions don't agree."(Nurse B: 491-493)

Although religion was discussed as a reason for health care professionals not to discuss donation, most religions support donotransplantation. Smith-Brew and Yani (1996) discussed that only a small percentage of individuals are aware of their religious doctrines regarding donotransplantation. The Catholic Church view donation as an act of charity and as ethical and moral. Furthermore, Buddhism believes that charity forms an integral part of a spiritual way of life and supports donation as an individual's choice. Judaism sanctions and encourages organ donation in order to save lives. Muslim, Hindu and Sikhism place great emphasis on the importance of giving and putting others before oneself (UK Transplant 2003b, c, d, e, f, g).

4.2.4.2 Preserving the palliative care philosophy

Protecting the speciality of palliative care was discussed as important for health care participants. Hospices are considered a place that enables people to die in a serene and peaceful environment (Lawton 2000; Walter 1994). Chaplain A for instance, was concerned that discussing corneal donation may detract from the care provided in a hospice and hence people's perceptions of hospice care.

> "The negative thing about asking is that they then actually may loose trust in the health care environment in that they feel that we're just hanging over people waiting for them to die. We are trying to provide people with a place where they feel safe and peaceful. I'm not sure they will feel that way about the place if they were asked about their eyes." (Chaplain A: 519-526)

Donotransplant Coordinator B discussed how one hospice nurse she spoke to found it difficult to understand the appropriateness of discussing corneal donation in a hospice, when the aim of care was to enable patients to die peacefully and that it seemed contradictory to facilitate them being "desecrated". One of the driving philosophies of the hospice movement is one of care rather than cure (Munley 1983). This philosophy of the hospice movement would support participants' conflict on whether donation could be an extension of the care they provided or not.

Nurse A felt that corneal donation was a "little too high tech" for the slow pace of hospices and was more suitable for the intensive care environment. The removal of a patient's eyes after they died did not appear to fit with participants' ideas of how patients should die within a hospice. They used terms such as "not normal", "freaky", and "too high tech" for the hospice. Even Johnson et al (1990) in their study exploring what hospices do, provided the example of organ donation being a 'technical' procedure performed within hospices. There are those that believe the introduction of technology to be an aspect of hospice care, which could potentially compromise the central ideals of the hospice movement and therefore be counterproductive to the hospice ethos (McNamara et al 1994; James and Field 1992; Siebold 1992).

McNamara et al (1994) suggested that the increased medicalisation of palliative care could compete with the ideal of a 'good death', which caused conflict between health care professionals, some who view the encroachment of medical technology to have a detrimental effect to patient care. Health care participants in this study used terms such as "total care" and "holistic care" to describe the "complete" care they were striving to achieve for patients to enable them to have a "good death". These terms link in with the hospice philosophy of a total framework of caring (Saunders 1998). Describing what they meant by a 'good death', participants used words such as "comfort", "peaceful", "dignity", "niceness", "autonomy", "openness", "compassion" and "natural". These findings are supported by Masson's (2002) when he interviewed hospice patients and deceased family member's about what they perceived to be a 'good death'. If health care, patient and bereaved family member participants believed a good death to include the given examples this could be a source of conflict when considering informing patients and families about corneal donation. Particularly as "comfort", "peaceful", "dignity", "niceness", "compassion" and "natural", were not words health care participants used in relation to corneal donation. In a number of cases these reasons were put forward as a reason why they may not discuss donation.

> "We do things nicely here and everyone has much more time, and it's a bit like a hotel and everything is geared towards making people feel more comfortable and there's this question (corneal donation), which might make people feel less comfortable." (Chaplain A: 640-643)

However, "autonomy" and "openness" were frequently used as reasons why discussing corneal donation may be important and will be discussed further in the category of 'Choosing'.

If palliative care health care professionals find the idea of medical technology a direct contradiction to what they are trying to achieve, then it is not surprising they find the concept of corneal donation a challenge. However, Seymour (2005) believes that palliative care has embraced new medical technologies to manage distressing symptoms, through for example, drugs, syringe drivers and palliative surgery. Therefore, those that are striving to retain what they perceive to be the founding principles of palliative care need to reconsider what this means and involves and whether corneal donation conflicts with those principles.

4.2.4.3 Emotional bond

There were many references in the data to the relationships formed between health care professionals, patients and their families. Participants' interpretation of this relationship appeared to be one of partnership. This partnership appeared to be an important factor for health care participants when they considered informing individuals about corneal donation, and for the patients and families to give a 'lack of objection'. Current literature on nurse-client relationships describes this bond as a partnership (Gallant et al 2002). There is a move away from nurses being an expert care provider to being a partner with the patient. The Government papers, 'Building on the Best' (DH 2003) and 'The NHS Improvement Plan' (DH 2004) endorsed the need for patients to be active participants and to have greater self determination and autonomy in relation to their health care needs.

The patient and bereaved family member participants stated that the partnerships formed with the nurses and doctors were important to them and had a direct impact on their ability to "cope" or "manage". Patient B spoke about how their community palliative care nurse had become a "friend" and "confidant", and how she looked forward to her visits. She spoke about how she felt confident that her nurse would "not let her down". Inextricably linked to patients' and families' concept of a partnership was the need for "trust" evidenced in phrases such as "I trusted her judgement". Bereaved Family Member B spoke about the time he was approached by a nurse and informed about corneal donation and he described how he trusted that the nurses would take care of his wife.

> "The nurse sat me down in a little room. She was the same nurse who was there when she went into the hospice. We were talking about what was going to happen when she died and she told me about the corneal donation. I was a little shocked she could do it but very pleased. The nurse talked about it more with me and my daughter. I knew she would take care of my dear wife." (Bereaved Family Member B: 522-530)

The development of a trusting relationship between the patient/family and the nurse/doctor was essential for patient and bereaved family member participants when considering who should discuss corneal donation with them. Reporting that they did not want a staff member with whom they were not familiar. Bereaved Family Member B, spoke about how the nurse who had been looking after his wife helped him make the decision to agree to corneal donation. The patient and bereaved family member participants appeared to place great value on a strong relationship with the hospice staff and their ability to feel confident and comfortable with a discussion relating to corneal donation. These findings are supported by Hughes (2005) and Carey and Forbes (2003) who also found that the hospice staff influenced patients' and family members' reaction to the discussion and the decision they made.

Although patient and family member participants believed that a familiar staff member was essential to their decision making. Health care participants were more concerned whether the relationship they developed with a patient and their family member would encourage or discourage them from broaching the subject. Health care participants reported that they believed a relationship formed over time, would be more conducive than an unfamiliar encounter.

> "Because we know the patients very well and the relatives very well, they could be supported through the discussion." (Doctor A: 116-117)

When considering situations where the relationship may discourage a discussion about corneal donation, the Eye Bank Coordinator, who had worked with several hospices, for many years, suggested that the long term relationships that were often formed between hospice health care professionals and patients could prevent them from discussing donation. She linked this to fears that such a discussion would upset the patients and family members. The fear of upsetting patients or family members was expressed by all the health care participants. Nurse A discussed how she found knowing the patient and family member made the conversation more difficult.

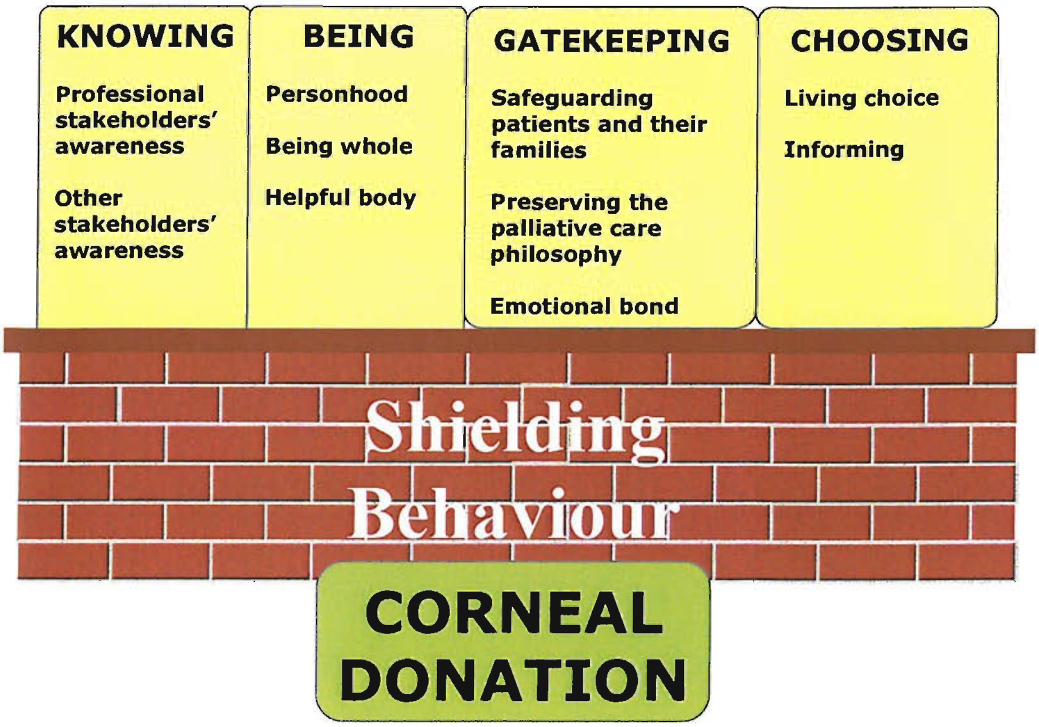
> "I ought to, I ought to be impartial about it and I do understand the necessity for having corneal donation. But it is very difficult, because if you are looking after somebody, and get quite connected to them and close to the family as well, it is a difficult subject to broach." (Nurse A: 54-58)

When asked why having a connection with the patients and family members made discussing donation more difficult, she talked about her concern that the discussion could change the relationship and affect the ongoing care she provided for the patient and her own job satisfaction.

Nurse B and both doctor participants spoke about how knowing the patient and family member was important when considering discussing donation although they believed they were rarely able to get to know the patient and family members on more than a professional level. Doctor A expressed that patients were often only at the hospice for days or weeks and that they could never learn everything about their life in such a short time. He felt they formulated "professional relationships" which endeavoured to include trust and honesty. Doctor B also discussed that "getting too close" can cause health care professionals to loose "objectivity" when considering informing patients and family members about end of life issues.

The formation and maintenance of a relationship between the patient, family and health care professional and how this influences the decision to discuss corneal donation could be understood using attachment theory (Tan et al 2005; Hunter and Maunder 2001; Goldberg 2000; Bowlby 1982). Attachment has been described as an emotional bond between two people based on an expectation that one or both will provide care and protection at a time of need (Goldberg 2000). Hunter and Maunder (2001) suggest that whilst the relationship that is formed between the clinician and patient may affect the patients' attachment styles and the clinicians' reaction to these styles, the attachment style of the clinician may also influence the relationship that develops. Tan et al (2005) believes that this attachment may contribute to the extent to which there is a mutual avoidance of emotional situations.

4.2.5 Choosing



This category is about patients and their family members being given the opportunity to choose whether donation is an option they would like to consider. Also, when and how donation should be discussed with them.

4.2.5.1 Living choice

Health care professionals who work in palliative care are in the unique position where their patient group is often aware of their mortality. This awareness of death enables the patient to be involved in the discussions and decisions regarding whether corneal donation is a choice they would like to consider (Wells and Sque 2002; Wells 2000).

All participants believed patients and their family members should be informed about corneal donation, however none of the health care participants routinely discussed donation with patients and families. Therefore, it appeared that high levels of belief about informing patients and family members about corneal donation, did not lead to positive action.

> "I know they are dealing with a lot of things, but yes, yes they should be informed. If they don't want it then they just have to say. But I think they

> have the right to know about it. The problem is we still don't ask."
> (Nurse B: 297-300)

Malecki and Hoffman (1987) who surveyed 124 nurses, found that although a majority of the nurses (95%) felt it was their professional responsibility to give people the choice about donation they still felt uncomfortable about obtaining consent from grieving families, with only 29 of the surveyed nurses having previously discussed donation.

Even though all participants suggested that the patients should be the individual who makes the choice, the reality in practice was that the family member generally made the decision. In a majority of cases health care professionals discussed corneal donation with family members when the patient was in the last few days of life or when they had already died. Hospice patients having the ability and capacity to make the decision about donation did not seem to motivate health care professionals to consider the patient, rather than the family, as the individual who should make the decision.

> "I think as a team we would approach the relatives more than the patient."
> (Doctor B: 212-213)

Why health care professionals appeared to feel more comfortable approaching the families rather than patients, near or after death, was considered. The data suggested that health care professionals approached family members rather than the patient because the "patients have been through enough", "the family have got to live with the decision, not the patient" and the perception that 'lack of objection' is legally required from family members. So as Nurse A stated, "there is no point talking to the patient". There was a perception that although patients should be able to have control (autonomy) over the decision about corneal donation health care participants were concerned and "frightened" that the law and their organisation would not protect them if they proceeded without gaining consent from the family. Although society has generally supported a moral and ethical stance that a 'lack of objection' should be obtained from the next of kin after an individual's death. This has changed with the implementation (September 2006) of the new Human Tissue Act (2004) which clearly states that staff should determine if potential donors have provided consent for donation before they died. If so then no further consent is required. Establishing the wishes of the patient may be difficult within the hospice setting as they do not have access to the ODR and therefore, unless health care professionals begin to routinely approach the patients they would need to continue to discuss the issue with families.

Health care participants all discussed using their judgement to decide the most appropriate person to inform, generally being the family member. This caused other stakeholder participants in the study to become emotive and challenge this approach. During Focus Group 2, the bereavement counsellors and chaplaincy team participants had a heated debate about who should be the decision maker. They appeared to put themselves in the position of a patient and considered how they would personally feel if a health care professional approached their family members about corneal donation and not them. They used words such as "insulted", "angry" and "childlike" to describe how they might have felt.

> "I feel quite angry that I might be lying in bed, not quite dead but nearly, and other people are discussing what's to happen."
> (Bereavement Counsellor A: (FG1) 228-229)

Both bereaved family member participants were informed about corneal donation after the patient had died. In both cases they seemed satisfied with the timing, attributing this to "knowing their (deceased) wishes". Bereaved Family Member B told how he and his wife saw a poster in their GP's surgery about organ donation about a year before her death. They had spent the time in the waiting room discussing their wishes. He said the conversation was informal and they did not sign donor cards, however, he remembered her wishes when the nurses spoke to him about it.

> "Knowing what she wanted made the decision easy."
> (Bereaved Family Member B: 387-388)

Studies (Sque et al 2006; UK Transplant 2005b; Sque and Payne 1996; Prottas and Levine-Batten 1988; Manninen and Evans 1985) have shown that knowledge of the deceased's wishes was an important factor in families' decisions to donate and that no knowledge of the deceased's wishes made the decision very difficult. As the two bereaved family member participants were aware of the patient's wishes regarding corneal donation it could be argued that the patients were still in control of the decision making process and that the family members were merely safeguarding this information for the patient until it was required. The bereaved family member participants reported how they would have been "disappointed" and "angry" if they had not been approached and found out later that their wives could have been potential donors. Bereaved Family Member A describing how "that would have been such a waste".

The two patient participants had considered organ and tissue donation as an option for themselves. Patient A had made a choice to be a potential donor and had discussed this with her family. As discussed previously, Patient A, who wished to be a donor perceived this was not possible due to her disease, so had not recently discussed it with her family or the hospice staff. She spoke about being "intrigued" when she was invited to take part in this study. Her personal view was that patients should be informed that corneal donation is an option as "it's my decision to make". She made comments that "it's not for everyone" and how it may upset some people if they did not wish to be a donor. Patient B had decided "it's not something I like the idea of", discussing how she wanted to be buried whole when she died. Although she did not wish to be a donor she said that she didn't mind being informed as she would "just say no thank you".

> "As patients we are asked to make choices about us all the time. This is no different to other decisions I've had to make. Decisions like having or not having treatments are far more difficult." (Patient B: 522-525)

Hughes' (2005) study concurs with the findings of this study. First, the positive reaction to being informed about corneal donation, regardless of the future intent and secondly, although broaching the subject of donation may cause distress it was a subject patients felt they should make the choice about. It could be argued that the patients in this and Hughes (2005) study were comfortable to discuss donation through virtue of agreeing to participate. However, it is widely agreed ideology that patients and their families want choice, empowerment and autonomy (Jensen and Mooney 1990), which is embedded within national policies such as 'Building on the Best' (DH 2003) and 'The NHS Improvement Plan' (DH 2004).

4.2.5.2 Informing

The focus of this sub-category is explored through three questions which relate to the aims of the study:-

1. Should hospice health care professionals have the option to opt out of discussing corneal donation on personal grounds?
2. When is the right time for the discussion regarding corneal donation?
3. How should patients and their family members be informed about corneal donation?

4.2.5.2.1 *Role Boundaries* (Should hospice health care professionals have the option to opt out of discussing corneal donation on personal grounds?)

All health care participants had conflicting opinions on whether it was their role to discuss donation and whether it should be a mandatory part of their practice. Although Nurse A did not want to donate her own organs and tissues she believed that this should not stop her informing patients and families of the option.

> "Despite how I feel about things, I still feel as a health professional, I do have, I should make people aware of it and do it the best way I possibly can." (Nurse A: 501-503)

Despite attempts to remain impartial, Nurse A's personal beliefs appeared to influence her ability to discuss donation as it was not an issue she broached with patients and families unless they initiated the conversation.

Some health care participants believed they should only discuss donation if they "feel comfortable" with the issue and if they have no "personal objections" to organ and tissue donation. Doctor B discussed how although she "didn't feel comfortable" discussing donation, there was a nurse who worked weekends who informed families.

> "We have one nurse who works two days a week, who is very keen, but people don't always die on her shift." (Doctor B: 313-314)

Such practice was not uncommon and was described by other participants as some staff being "more proactive about the issue". They reported that "it should be optional" and guided by "clinical judgement". Those that believed it should be part of end of life discussions seemed to believe that by making it the choice of the individual health care professionals could lead to "inequalities". Inequality was described by all the health care participants. The definition of inequity is the act of being unfair or unjust (Oxford English Dictionary 1999). "Unfair" being the word used by participants to describe the choice of action by health care professionals.

> "You get a few committed people but they're not going to be on call 24 hours a day, and unfortunately a lot of the good work falls to a few which I do think is unfair, and rather a shame." (Eye Bank Coordinator: 318-321)

This led to only some patients and families being given the option of donation: the deciding factor being if certain health care professionals were available.

The findings in this study regarding role boundaries is supported by Kent (2002) who found that for an undisclosed number of participants there were concerns expressed about role boundaries, indicating that discussing donation fell outside the nurses' remit. Wakeford and Stepney (1989) believed that there could be an increase in referrals for organ and tissue donation if it was accepted by health care professionals that it was part of their professional duty.

4.2.5.2.2 When to inform (When is the right time for the discussion regarding corneal donation?)

A number of participants discussed the importance of the timing of the donation discussion and that there should be "no blanket rule" on when it should be broached. Several stages of the patient journey were suggested as possible points to consider discussing corneal donation. These ranged from; prior to admission, when a day care patient, on admission to the hospice, when trust has been established, when discussing other end of life issues and after death with the family. There was no clear consensus of opinion.

The timing of the conversation with families is considered fundamental to the decision and outcome of the discussion (Sque et al 2006; Burroughs et al 1998; MORI 1995). However, these studies relate to the ICU situation and may not reflect the hospice setting. In ICU patients are unable to be involved in the decision making process, and death is often sudden and unexpected. Whereas, palliative care patients are able to be involved in the decision making process (Wells 2000) and death is generally expected.

Although, the 'normal practice' for health care participants, was to inform families about donation in the patient's last few days of life or soon after death, there was a general feeling that patients should be informed "early" when they were "well".

> “My gut feeling is that by the time patients have come in here it’s too late. Because they are getting patients who are much more sick than they ever used to be.” (Bereavement Counsellor B (FG2): 203-205)

The doctor participants suggested a discussion around corneal donation could be considered as part of the conversations that happen around “end of life planning” and “choice” in the community. The Government policies ‘Building on the Best’ (DH 2003) and ‘End of Life Care Initiative’ (DH 2004), highlight the need for health care professionals to facilitate patient involvement in choices around end of life care. One of the suggested initiatives to facilitate patient choice is the development of the Gold Standards Framework (GSF) in the community. The doctor participants discussed how informing people about corneal donation could be “fed in” or “included” at an “appropriate time” as part of the GSF, whilst patients were “well enough” to make the decision. The patient participants suggested that if they were informed about donation when they were “well” it would give them the opportunity to “think about it”. The concept of “being well” was repeatedly used when discussing appropriate timing of a conversation. Patient A discussed how when she was feeling “unwell” she was unable to process information and make decisions for herself. Lickiss et al (2004) discusses how uncontrolled physical and psychological symptoms significantly reduce the terminally ill patient’s ability to address concerns. Day hospice was another area several participants considered a possible place for health care professionals to discuss donation. Participants talked about how patients were often “well” and therefore may provide opportunities to discuss corneal donation. The day hospice patients who participated in Hughes (2005) study confirmed the need to be informed “early” when they were “still well enough” to make decisions.

The bereaved family members who were informed about corneal donation after their relative’s death both felt “satisfied” with the timing. However, Bereaved Family Member A, on reflection, believed it may have been easier on the family to make the decision if they were aware of the option before the patient’s death “those days before”. Nurse B and Doctor A, who worked in the same hospice, spoke about how implementing the Liverpool Care Pathway (LCP) for the Dying Patient into their practice had facilitated improvements in corneal donation rates. They had adapted the LCP to incorporate the need to inform families about the option of corneal donation.

4.2.5.2.3 *Methods to inform* (How should patients and their family members be informed about corneal donation?)

Alternative methods to a direct discussion, or to "assist" with the conversation were considered by all participants. These methods included the use of "leaflets" and "posters". Nurse A felt that by placing leaflets on corneal donation in a "patient day room" they were "being informed". She believed that it was then "the responsibility" of the patient or family to approach staff if they wanted further information. The majority of participants discussed how leaflets would be appropriate to use as secondary information and should not be used as an alternative.

> "Leaving leaflets around is a cop out. We have the skills of communication so should use them. Leaflets should be available if they (patients and families) want more info." (Doctor B: 555-557)

There is limited literature to support the use of secondary sources of information to complement and verify information given to palliative care patients (Kirk et al 2004). However, Bereaved family member B described how he found reading "the leaflet" on corneal donation helpful when he got home.

The current practice of one hospice was discussed by doctors and nurses in Focus Group 1. They discussed how the introduction of the Liverpool Care Pathway had successfully led to the use of a leaflet (www.lcp-mariecurie.org.uk) for family members, which informed them about changes that may happen when a patient was dying. This leaflet was offered to families when a multidisciplinary decision had been made that the patient was dying. The hospice had devised and implemented an information sheet about the option of corneal donation, which was given to families with the leaflet. The nurses discussed how the leaflet made them feel "more comfortable" broaching the subject as it was "not new" or a "shock" to the family when they initiated a conversation.

> "Because we have a more structured leaflet that mentions it, so that comfortably brings the subject up." (Nurse A: (FG1): 157-58)

Nurses and doctors within Focus Group 1 expressed pleasure that the new approach had led to an increase in staff discussing corneal donation and a "positive change" in their practice. Nurse A (FG1) explained how she used the leaflet as "a tool" to establish whether family members wanted further information about corneal donation.

Previous studies highlight palliative care patients and families desire for varied methods of information about corneal donation (Hughes 2005; Carey and Forbes 2003; Wells and Sque 2002; Wells 2000). However, none of these studies have considered the content of the information regarding corneal donation in the palliative care setting. This is an area that requires further examination.

4.3 Summary

This chapter has presented the findings and discussion. 'Shielding Behaviour' provides a theoretical framework to explain corneal donation within the hospice setting that considers the behaviour and feelings of stakeholders. These findings not only represent the views of those directly involved in palliative care but also stakeholders external to the hospice setting who also influence corneal donation within this clinical area. The theory was constructed from the integration of five categories: 'Shielding Behaviour', 'Knowing', 'Being', 'Gatekeeping' and 'Choosing'. 'Shielding Behaviour' was identified as the core category as it was the most pervasive theme expressed by participants.

The desire 'not to do harm' was essential for participants if corneal donation was to be discussed. Concerns about doing harm versus the possible benefits of corneal donation were identified by all the participants. Although there was an acknowledgement that individuals should have choices at the end of life, corneal donation did not conform to health care professionals' ideals of a 'good death'. Participants believed this could be as a direct consequence of insufficient knowledge of the donotransplantation process and inability to visualise the long term benefits for recipients. Although participants agreed that individuals should be informed about donation, knowledge and attitudes held by health care professionals affected their ability to make the decision to inform patients and families.

In next chapter I will conclude my study by critiquing the research process and make recommendations for clinical practice and suggestions for future research.

Chapter Five:
Reflections, Recommendations and Conclusion

5.1 Introduction

The previous chapter provided the findings and discussion of the study. This chapter is divided into three sections. The first section provides a reflection on the methodology and methods used throughout the study, highlighting any difficulties encountered and their resolutions. The second section addresses what contribution this study provides for clinical knowledge and practice and the third section presents the implications of the study and recommendations for education, clinical practice and further research. This is followed by the conclusion of the study.

5.2 Methodological and method critique

5.2.1 Using Grounded Theory methodology

The nature of the study required a qualitative approach as it was an exploratory study. Qualitative methodological approaches that were considered included ethnography and case study. Phenomenology was rejected as I was not investigating the lived experiences of a specific group who have experienced the same phenomena (Creswell 1998). Ethnography was considered however, the focus of this approach is the interpretation of a cultural or social group and although I was investigating stakeholders involved in the corneal donation process the study was not aimed at any specific organisation or social group. Case study methodology was a possible option as it is flexible and allows the use of multiple sources of data i.e. documents, interviews, observations (Creswell 1998). Although Case study maybe useful to advance the findings of this work by allowing comparisons between policy and practice within other hospices, as a preliminary exploration grounded theory was deemed the most appropriate methodology. This was due to its flexibility in selecting participants as the theoretical model evolved and in gaining insight into the views and feelings of stakeholders involved in the corneal donation process within the hospice setting.

Glaser and Strauss (1967) suggest that the researcher starts with an idea. This study was founded on curiosity and the desire to explore further the findings of my MSc study (Wells 2000) within a framework that allowed for the development of a theoretical explanation. Through using a grounded theory approach the study has yielded rich and detailed accounts of the participants' experiences and thoughts, as well as a theoretical description.

During the study I developed a broad knowledge of grounded theory and the many intricacies that are involved. At times this caused confusion and the need to revisit data and analysis. On reflection, this is partly due to the different schools of thought and the dichotomy between Glaser's (1978, 1992) and Strauss and Corbin's (1998) approaches which were discussed in Chapter 3.

5.2.2 Gaining ethical approval

Multi Centre Ethics (MREC) approval was sought in August 2002 and was granted pending minor amendments. These pertained to the structure of the patient information sheet and the need to consider non-english speaking participants.

I was naive to think that I could commence data collection immediately after MREC approval was granted. I was also required to inform the five Local Regional Ethics Committees (LREC) of the MREC approval. The LREC's informed me of the need to gain each participating NHS Trusts and voluntary organisations agreement through their Research and Development structures. This posed a challenge as they all requested to review the research proposal. Two of the NHS Trusts also required that I applied for an honorary contract. Unfortunately, this caused a five month delay in commencing the study. The process of gaining ethical approval revealed inconsistencies in how research governance structures were implemented across different NHS Trusts and voluntary organisations, causing the process to be confusing and time consuming.

5.2.3 Sampling and recruitment

The first five, Phase 1 interviews took place between April and November 2003. My original thought was to initially interview the eye bank coordinator, ophthalmic surgeon, and one of the donotransplant coordinators to gather background information about the donation process, which could be used to inform subsequent interviews. However, this proved unachievable as the donotransplant coordinator resigned her position, creating a need for further recruitment. The ophthalmic surgeon cancelled his interview four times due to clinical commitments, leading to unexpected delays. Therefore, whilst waiting to arrange more convenient times, I interviewed hospice health care professionals and then used any relevant findings from those interviews to inform interviews with the donotransplant coordinator and ophthalmic surgeon. In retrospect this was beneficial to data collection and analysis. It became apparent during the analysis of the hospice health care professionals' interviews that there were issues that the donotransplant coordinator and ophthalmic surgeon may be able to illuminate. Some of these issues were the priority of corneal donation in the dontransplantation arena, the role of donotransplant coordinators during the corneal donation process and the information provided for corneal recipients regarding the source of donated tissue. This method of data collection is conducive with theoretical sampling.

Interviewing patients with a life limiting illness and bereaved family members was a complex undertaking, principally because of difficulties with gaining access. The patients were originally going to be approached by day hospice staff. However, there was discomfort amongst the day hospice staff about broaching the subject of participating in a study which deals with a sensitive unexplored issue and concern about the patients' reactions. Through discussion with the staff, it was suggested that the community specialist palliative care nurses (CSPCN), who often have long term involvement with the patients and families and had experience in dealing with sensitive issues, would recruit the two patients. A majority of the CSPCNs also felt uncomfortable discussing the study with patients. A concern about patients' reactions was reflected in the findings of this study. The concerns the day hospice staff and CSPCNs had about causing harm or distress was not borne out as the two patients who were approached both agreed to participate. The CSPCNs who recruited the patients reflected back to me that they were surprised how readily the patients agreed to participate. I also required the assistance of CSPCNs to recruit the bereaved family members. There was less hesitancy by CSPCNs about this group as they were discussing the study with individuals who were already aware of corneal donation due to the donation of corneas from a deceased family member. Therefore, they were not broaching a new subject.

One of my concerns was that some of the health care participants knew me. I anticipated that there could be issues of familiarity and over identifying with participants' answers, which could lead to a particular kind of interpretation. This did not appear to be a problem and was resolved by keeping an open mind and by asking for clarification of ideas. Two of the participants (one nurse and one doctor) expressed finding it easier talking to me about personal and sensitive issues rather than a stranger. Holloway and Wheeler (1996) concur with this finding by suggesting that shared language and norms can be advantageous, leaving less room for misinterpretation. To ensure I accurately described what these participants were saying, it was their transcripts that I had reviewed by another researcher.

5.2.4 Interviews

When participants were being recruited to the study a common reaction I encountered was "I don't think I will be useful", seemingly believing they knew nothing about the issue, so would not be able to add value to the study. This was particularly expressed by the patients, bereavement counsellors and chaplains. The reality was that they brought a crucial perspective to the study and feedback from them indicated surprise and even pleasure that they were able to share so much. Several using the platform to explore further the issue for themselves or their professional role. What this could suggest is that those staff who work within the hospices who are not nurses or doctors do not perceive that corneal donation is part of their role. However, once they had the opportunity to talk and reflect on their thoughts through the interview process, there appeared to be elements of their role which they believed could benefit and improve the corneal donation discussion and future support.

It was not my intention for the interviews to offer any form of therapy. However, during the patients' and bereaved family members' interviews it became apparent that this was difficult to achieve and the interviews were perceived as therapeutic. This may have been partially due to the participants being aware that I was not only a researcher but also a palliative care nurse. They used terms such as "you know what I mean", "have you seen that before?" and "What do you think?". Also, it provided the patients and family members with an opportunity to openly express their feelings (Lowes and Gill 2006). Lowes and Gill (2006) and Kvale (1996) suggest that by providing a forum for participants to discuss an emotive subject, catharsis is probably unavoidable and can be positive for them.

Fontana and Frey (2005) discuss the importance of how the researcher presents themselves. The implications being that it leaves a profound impression on the participant and will affect how they interact during the interview. Despite my best efforts to present myself as a researcher for the purpose of the interview, it quickly became apparent that it would be difficult to avoid the influence of my clinical role on the interview process and something that to some extent could be beneficial. I would like to propose that the clinical experience I have in palliative care was invaluable and to some extent crucial to maintain a safe environment for the patients and bereaved family members. Having the clinical skills to manage difficult and sensitive situations allowed me to ensure a safe environment and pick up important cues, whilst maintaining a focus on the purpose of the study. Kvale (1996) and Morse (1994) suggest that therapy could be an incidental element of the qualitative interview by providing the participant with a listener. This allowed them the opportunity to be reflective and to vent repressed emotions (Colbourne and Sque 2004). Bereaved Family Member B wrote to me after the interview thanking me for giving him the opportunity to talk about his wife and share his experience. Also, Patient A asked me for further information on how to become a corneal donor.

5.2.5 Data analysis

A critique of the data analysis process is provided in Chapter Three. However, I would like to briefly explore how the study changed as it progressed and to return to the subject of data storage.

The initial research proposal involved a three phase study. The first and second phases being interviews and focus groups, whilst the third planned phase was to be a postal questionnaire to all UK hospices, developed from the findings of the first two phases. During the interim assessment it was suggested that the first two phases would provide sufficient data to produce a theoretical explanation of the participants' experiences. It is anticipated that the postal questionnaire will be a future piece of work.

I originally anticipated transcribing the audiotapes myself, however due to time constraints I accepted a medical secretary's offer to do the transcribing. I was concerned that this would hinder my understanding and feeling for the data. However, this did not occur and the transcripts were ready to examine quicker avoiding loss of thoughts and ideas that had been gained during the interviews and focus groups.

I had heard varying opinions on the use of data management packages such as NUD*IST 5. If I had interviewed less than ten participants I would have opted out of using a package and managed the data manually. However, with a larger number of interviews, manual data management becomes more difficult. Therefore, NUD*IST 5 seemed a positive option. I had never used the package before so undertook training prior to commencement. During the initial stages of data analysis, I frequently lost data, had difficulty inputting information and subsequently retrieving data. However, the rewards for perseverance came when writing this document as data were easy to access and work with.

5.3 Contribution to clinical knowledge and practice

The findings of this study confirm and build on many of the findings of previous research into tissue donation within the hospice setting (Hughes 2005; Carey and Forbes 2003; Wells and Sque 2002).

What differs between previous studies on corneal donation within the hospice setting and this piece of work is that prior research has focused on specific sample groups e.g. Hughes (2005) only interviewed patients with a life limiting illness, Carey and Forbes (2003) only interviewed bereaved family members and Wells and Sque (2002) only considered the views and feelings of hospice health care professionals. What this study provides is an explanation of the views and feelings of participants from the perspective of a variety of stakeholder groups involved in corneal donotransplantation and how their interactions and behaviours influence the process within the hospice setting providing a multi-dimensional viewpoint. The following findings of the study are considered new knowledge.

- The findings highlight the challenges and emotions health professionals experience when making decisions between respecting patient's autonomy to make their own decisions versus shielding them from potential harm. This confirmed the findings of Wells and Sque (2002). However through collecting data from stakeholders other than health care professionals the findings showed that even though there was a perceived risk of causing distress there was no evidence from participants that they had either experienced this or heard of this occurring. Even the patient and bereaved family participants did not believe that if the issue of corneal donation was broached in a sensitive manner by a familiar health professional it would cause further distress.
- Health care participants acknowledged their limited knowledge and understanding regarding the experiences of corneal recipients and how the donation of a cornea can have significant impact on a recipients' quality of life. Health care participants expressed how knowing the outcome of corneal donation may influence and encourage them to consider discussing corneal donation. Wells and Sque (2002) only identified health professionals' limited knowledge in the process of corneal donation for the donor and not the outcome for recipients.
- The findings of this study not only confirm Hughes (2005) suggestion that hospice patients who had cancer believed they may contaminate recipients but also exploring this issue further. The ophthalmic surgeon participant was able to clarify that this was not considered a risk unless the donor had a haematological malignancy and the fear of contamination by the patient participants was not expressed by the corneal recipient participants.
- The study explored the emotions and feelings that the eyes and sight evoke for individuals, and how this influences their ability to consider corneal donation after death. Those participants who believed that the eyes had a link with a persons soul found this influenced their ability to consider

corneal donation. This was also the case for participants who considered the eyes to be a strong symbolism of the person who had died.

- Although the theory of 'Shielding Behaviour' supports many of the findings of Kent's (2004) work, which puts forward the concept of 'protection behaviour' as an explanation for nurses' reticence to discuss organ and tissue donation. The theory of 'Shielding Behaviour' explores beyond just nurses behaviour and considers the behaviour of other stakeholders involved in the corneal donation process. The findings of this study show that it is not only nurses who have a desire shield individuals from harm, but that this behaviour is also exhibited by the other stakeholders.
- By using a grounded theory approach, the new theory of 'Shielding Behaviour' has been produced. This theory is defined as 'the desire to shield from harm all those affected by the corneal donation process within the hospice setting.' Although this theory applies to the behaviour of stakeholders involved with corneal donotransplantation within the hospice setting it could be applied to other clinical environments such as intensive care units and general wards where patients are admitted and cared for with life limiting illnesses.

One of the aims of this study was to provide a theoretical explanation of the views and feelings of stakeholders involved in the corneal donation process within the hospice setting. A key feature of a grounded theory approach is the generation of a theory to explain the phenomena being studied. Glaser and Strauss (1967) state that two types of theory are produced through grounded theory, substantive and formal theory. Strauss and Corbin (1998) attempted to distinguish the differences between a formal and substantive theory by describing a substantive theory as the study of a phenomenon in one situational context and a formal theory as the study of phenomena which can move across different situations. The theory of 'Shielding Behaviour' has been proposed as a substantive theory as it is restricted to corneal donation in the hospice setting and as it explains the immediate phenomena of interest.

A substantive theory is a strategic link and builds a foundation to the formulation and generation of formal theory. The theory presented could lay the foundations for formal grounded theory by examining the theoretical categories in other areas of healthcare where stakeholders may respond with 'shielding behaviour'. To develop formal theory more completely the phenomenon would need be studied in multiple contexts and applied to a wider range of disciplinary concerns and problems (Strauss and Corbin 1998).

As a substantive theory the idea of shielding behaviour may only be applied to the setting in which the theory was developed. However, The findings of this study and the theory of 'Shielding Behaviour' has the potential to become a formal theory as it could be adapted and applied to a wide range of healthcare practices and experiences e.g. the nurses behaviour when carrying out the necessary pre-operative screening, ensuring patients are nil by mouth and administering pre-operative drugs to assist the patient to relax could be explained by the theory of 'Shielding Behaviour'.

As this is a relatively small study it may not be transferable beyond the study participants, but may have meaning to those in the palliative care field. Strauss and Corbin (1998) discuss how the purpose of grounded theory is to develop a theory that explains the phenomena being studied rather than considering transferability. Therefore, this study and its findings should be considered as an explanation of corneal donation in a given place and time and is the result of the views and feelings of the population who participated in the study. It provides deep and detailed accounts of the participants' experiences as well as theoretical description. Through the provision of 'thick description' (Geertz 1973) it is hoped that the findings of this study will motivate other researchers interested in corneal donation in the hospice setting to reach a conclusion about whether transfer is possible (Lincoln and Guba 1985). By providing a clear description of the participants the reader can judge if they can relate to the population and findings to their own situation. Preliminary dissemination of my findings to colleagues has confirmed that transferability may be possible. Many have shared how they can relate to what participants have expressed and shared with me. They reported how the presentation of findings encouraged them to reflect on their own behaviour and how this may impact on their practice towards corneal donation.

The theory that is presented to explain the phenomena being explored is specific to corneal donation in the hospice setting. However, what became clear during theory development was that corneal donation cannot be considered as an isolated event. Rather, it needs to be considered along side the wider issue of end of life care and take into account the many variables this embodies.

5.4 Implications for education and clinical practice

Identifying the implications of this study for education and clinical practice is essential to develop strategies to enable the inclusion of corneal donation as part of end of life care for patients. The following recommendations are presented in relation to education and clinical practice.

- With choice and end of life care being high on the health care agenda, along with the need to increase the donor pool, there needs to be educational initiatives to highlight the importance of providing patients and their families with choices about organ and tissue donation. Organ and tissue donation is rarely included within end of life care education and training programmes, both at pre and post registration levels of nursing. When end of life care educational programmes are being developed, curricula need to reflect the importance of organ and tissue donation as a choice in end of life care. This should include information sharing, own awareness, inclusion criteria, the donation process and the effects of a transplant on the corneal recipient.

- Evidence shows that some hospices were more proactive in their approach to the donation process than others. In those hospices where corneal donation was included as part of end of life care, although there was some reticence from staff, the bereaved family members and patients were generally in favour of corneal donation being offered as a choice. Palliative care staff should consider informing patients about corneal donation as part of end of life discussions. This may enhance patient choice and allow them to make decisions about their own bodies.

- There is a need for health care professionals to consider their own feelings and attitudes about corneal donation in the hospice setting as they need to feel comfortable, confident and skilled to initiate discussions. Therefore, each hospice needs to develop strategies that encourage discussion regarding corneal donation in a supportive environment. Leaders are essential to this move and they need to facilitate a proactive approach to corneal donation, which empowers and supports their staff.

- How and when patients and families wish to be informed about corneal donation may vary. Hospice staff need to consider various forms of information sharing. Along side information, health care professionals need to use their pre-existing communication skills in discussing sensitive issues to identify appropriate opportunities to inform individuals about corneal donation.

5.5 Recommendations for further research

The suggested implications for education and clinical practice have highlighted potential areas of future research about corneal donation in hospices. The recommendations provided are drawn directly from this study.

- There is a need to expand this study to include more patients with life limiting illnesses, their family members and corneal recipients.

- There is a need to develop this work further by generating a postal questionnaire from the findings of this study. This would allow targeting of a larger population to explore hospice practice. Postal questionnaires are considered a viable method of gaining data from a larger, geographically diverse population (Simmons 2001). A self-completion questionnaire would be posted to all hospice ward managers/matrons in the United Kingdom. The content of the questionnaire will likely contain both closed and open questions about corneal donation practice. This would allow a national perspective and the ability to assess regional differences as corneal donation is a relatively unexplored area of hospice practice.

- An area of potential research is to examine the knowledge and attitudes of hospice nurses and whether they differ from nurses working in other clinical environments. The questionnaire developed by Sque et al (2000) to explore nurses' attitudes regarding organ and tissue donation could be adapted to explore hospice nurses' knowledge and attitudes and if there are any differences from the findings of Sque et al's (2000) original study.

- Further study is required to determine appropriate strategies to inform patients and their families about the option of corneal donation. What has been established from this study is that there needs to be different approaches to provide information about corneal donation. However, what this could include requires further investigation. There are a number of methodological approaches that could be used to examine this issue i.e. an ethnographic observation of discussions about corneal donation and questioning of patients and families about information giving.

- The findings of this study indicated that there may be differences in the experiences of corneal recipients to those receiving other organs through transplantation. Also, the hospice staff demonstrated that their understanding of the corneal donation process ceased once the eyes had been retrieved from deceased patients. This did not provide them with an understanding of the outcome of corneal transplants and the implications and changes it has on recipients' lives. An area of potential research is to explore the lived experience of corneal recipients that would inform practitioners in palliative care.

5.6 Conclusion

The aim of this study was to explore corneal donation as an option to be discussed with patients and their families within the hospice setting and to begin to explain the possible impact of offering it as an option at the end of life. The substantive theory of 'Shielding Behaviour' was developed to explain the aim by describing the views and feelings of stakeholders who would be involved in corneal donation within the hospice setting.

I have explored the perceptions and feelings of stakeholders regarding corneal donation. Health care professionals found corneal donation, being part of end of life care, difficult to conceptualise. During data analysis it became apparent that knowledge regarding the eligibility of patients to donate their corneas was an issue. Patients, family members and a number of health care professionals were unaware that patients who die within the hospice setting are potential donors and a valuable and untapped source of tissue. There was a misconception held, not only by the other stakeholders but also health care professionals that cancer was a contraindication to corneal donation and that organ and tissue donation only occurred in the intensive care environment. By discussing corneal donation with patients and their families, those individuals who have made the choice to be a donor after their death, are given the opportunity to fulfill their wish. The awareness of eligibility to be a donor could be a powerful influence on willingness and behavioural commitment to donate.

I have examined stakeholders' views on informing and discussing the option of corneal donation with patients and family members. The findings identified that health care professionals need to acknowledge corneal donation as an option in end of life care. They need to develop greater awareness about the potential benefits for patients, families and recipients. The findings have confirmed the results of Hughes (2005), showing that accurate and balanced decisions regarding when and how patients and families are informed is essential. There is no one way of informing individuals and it is the skill of the health professionals to identify the most appropriate time. The ability of health professional to determine when and how to discuss corneal donation with patients and families will be based on 'knowing' the patient and family and being able to provide a trusting and safe environment.

I have explored stakeholders' behaviour in relation to corneal donation within the hospice setting. Although there was an acknowledgement by health care professionals that individuals should have choices when considering the care they receive at the end of life, discussing corneal donation did not conform to their ideals of a 'good death'. Participants believed this stance could be as a direct consequence of insufficient knowledge and understanding of the donotransplantation process and inability to visualise the long term effects for corneal recipients, focusing only on the care of the dying patient. This was expressed in the health care professionals' desire to shield the patients and family members from a situation that they were concerned would inflict harm or distress.

Finally, I have been able to establish what stakeholders perceive to be the effects of a discussion about corneal donation on patients and their families by showing that the concern of the health care professionals that a discussion may cause harm was not expressed, as an issue, by the patients and bereaved family members. There was no indication from the findings that the patients and families believed a discussion regarding corneal donation would cause them any detrimental effects if the timing of the discussion was considered on an individual basis, by a health care professional who had a 'good' relationship with the patient and family. The patients and bereaved family members were able to provide valuable and insightful data on the effects of being able to make a decision about donation. Whilst the corneal recipients were able to share their positive experiences and the improvement in their quality of life by receiving a cornea from an individual who had died and been given the opportunity to fulfil their wish.

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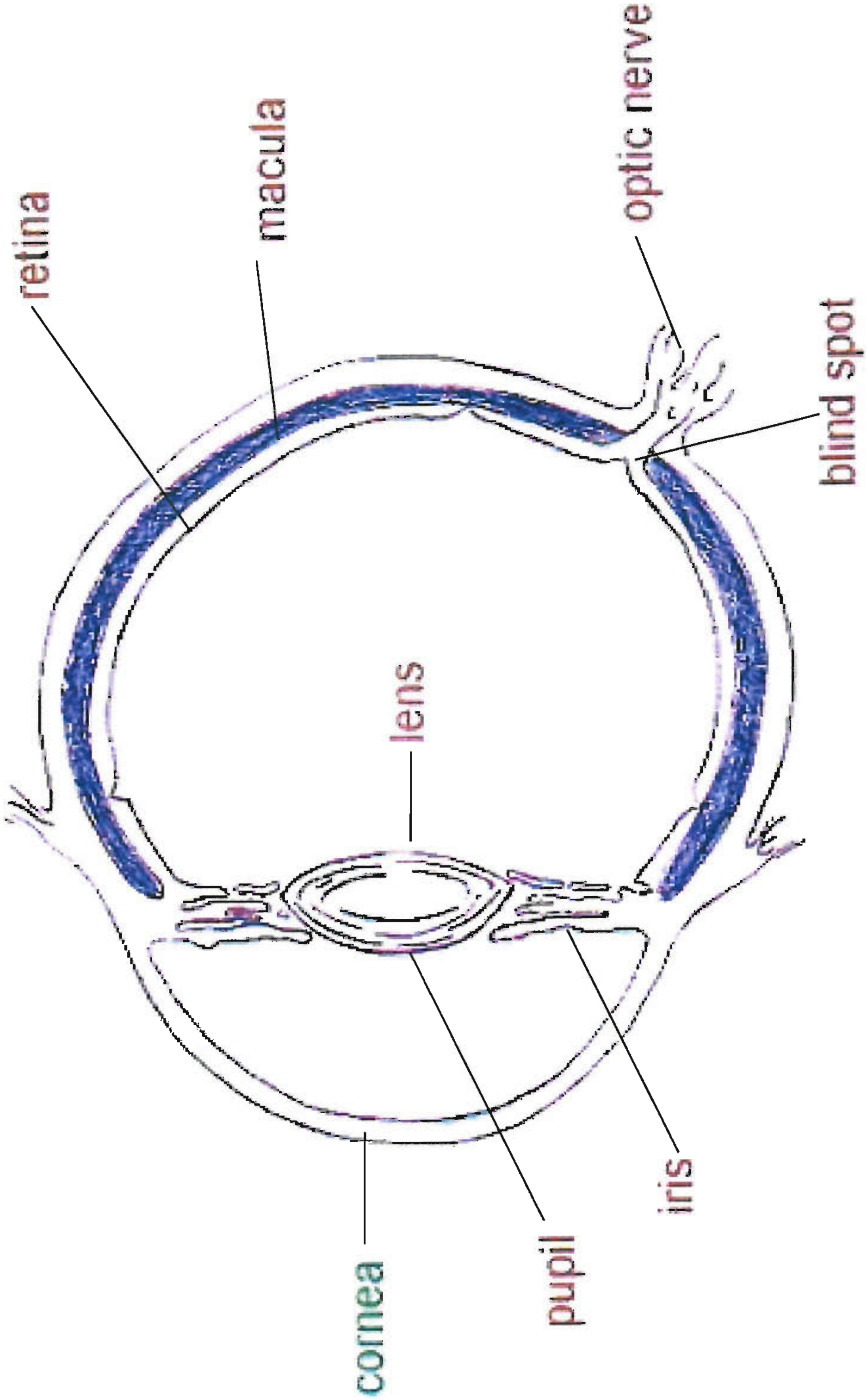
Appendices

Appendix 1

The Eye



Appendix 2

Literature Search Strategy

Primary Sources

A preliminary literature review was carried out at the beginning of the project and constantly updated throughout the period of the project (November 2001 – July 2006).

The literature search used several electronic databases:

- Medline
- CINAHL
- PSYCHLIT
- EMBASE
- British Nursing Index
- Cochrane

Only papers which were research based were considered.

Language

It was not intended to restrict the review to studies written in the English language. However, during the search process there were no studies found which required translation.

Search words and terms

Chapter 1: Tissue donation

- The key words and phrases used initially to identify a broad overview of the research field were:
    - Organ donation, tissue donation, organ transplantation, tissue transplantation, corneal donation, donotransplantation, non heart-beating donation.

- To narrow the search these were combined with the words:
    - attitudes, knowledge, views, outcomes, beliefs, experiences, and perceptions.

	Inclusion Criteria	**Exclusion Criteria**
The Population	Adults (18 years and over) Studies relating to heart beating and non-heart beating donors.	Children Studies related to living donors.
The Intervention	Donation Organ and tissue donation in all clinical areas.	Transplantation The physiology of organ and tissue donotransplantation
The Outcome	History Knowledge and Attitudes	Future technological developments

The Study Design	All studies which meet search criteria Studies published between 1985 to present	All studies which do not meet search criteria

The search criteria revealed a total of 129 papers. After withdrawing repetition and papers not based on research a total of 40 papers were rejected. A total of 89 papers were reviewed.

Chapter 2: Specialist palliative care and corneal donation

- The key words and phrases used initially to identify a broad overview of the research field were:
    - Hospice, palliative care/medicine, palliation, death, dying, end of life care, terminal care.

- To narrow the search these were combined with the words and phrases:
    - History, definition, services, good death, bad death, medicalisation, technology, views, beliefs, attitudes, care, perceptions, research, environment, philosophy, communication, corneal donation, tissue donation.

	Inclusion Criteria	**Exclusion Criteria**
The Population	Adults Hospice and palliative care services	Children Studies where hospice and palliative care services are not being used.
The Intervention	Medicalisation of palliative care 'Good Death' ideology Strategies to facilitate end of life care The provision of palliative care for those individuals with and without a cancer diagnosis Tissue donation in palliative care	Symptom control management Tissue donation in non-palliative care environment
The Outcome	Growth of the hospice movement in the UK	Palliative care outside the UK
The Study Design	All studies which meet search criteria UK based studies Studies published between 1990 to present	All studies which do not meet search criteria

The search criteria revealed a total of 228 papers. After withdrawing repetition and papers not based on research a total of 120 papers were rejected. A total of 108 papers were reviewed.

Secondary sources

Further sources of literature were identified through:

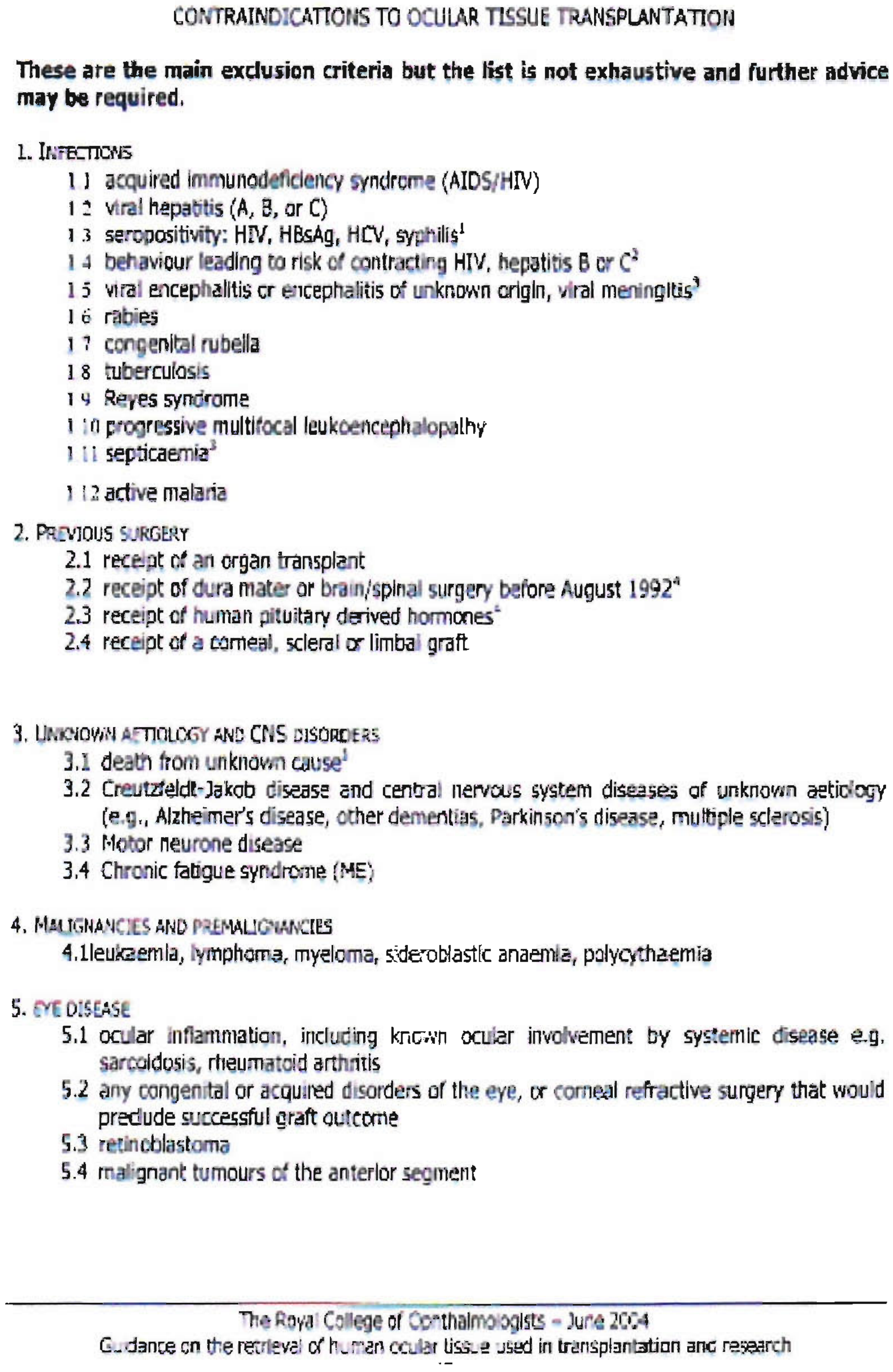
- Regularly hand searching current journals for new literature
- References from research identified in initial searches
- Personal communication with experts in field
- Books
- Web searches
- Unpublished or grey literature

Appraisal questions

Several questions were asked of all research studies irrespective of the methodology which was used. The questions are listed below and were adapted from Crombie (2001).

- Are the aims of the study clearly stated?
- How was the sample selected?
- How was the sample size calculated and was it justified?
- Are the measurements likely to be valid and reliable?
- If statistical methods were used were the methods described?
- If survey instruments were used were they adequately described?
- How were survey questions developed?
- Did any unexpected events occur during the study?
- Were the basic data adequately described?
- What do the findings mean?
- How do the results compare to other studies?
- What implications do the study results have for practice?

Appendix 3



CONTRAINDICATIONS TO OCULAR TISSUE TRANSPLANTATION

These are the main exclusion criteria but the list is not exhaustive and further advice may be required.

1. INFECTIONS
    - 1.1 acquired immunodeficiency syndrome (AIDS/HIV)
    - 1.2 viral hepatitis (A, B, or C)
    - 1.3 seropositivity: HIV, HBsAg, HCV, syphilis[1]
    - 1.4 behaviour leading to risk of contracting HIV, hepatitis B or C[2]
    - 1.5 viral encephalitis or encephalitis of unknown origin, viral meningitis[3]
    - 1.6 rabies
    - 1.7 congenital rubella
    - 1.8 tuberculosis
    - 1.9 Reyes syndrome
    - 1.10 progressive multifocal leukoencephalopathy
    - 1.11 septicaemia[3]
    - 1.12 active malaria
2. PREVIOUS SURGERY
    - 2.1 receipt of an organ transplant
    - 2.2 receipt of dura mater or brain/spinal surgery before August 1992[4]
    - 2.3 receipt of human pituitary derived hormones[4]
    - 2.4 receipt of a corneal, scleral or limbal graft
3. UNKNOWN AETIOLOGY AND CNS DISORDERS
    - 3.1 death from unknown cause[1]
    - 3.2 Creutzfeldt-Jakob disease and central nervous system diseases of unknown aetiology (e.g., Alzheimer's disease, other dementias, Parkinson's disease, multiple sclerosis)
    - 3.3 Motor neurone disease
    - 3.4 Chronic fatigue syndrome (ME)
4. MALIGNANCIES AND PREMALIGNANCIES
    - 4.1 leukaemia, lymphoma, myeloma, sideroblastic anaemia, polycythaemia
5. EYE DISEASE
    - 5.1 ocular inflammation, including known ocular involvement by systemic disease e.g. sarcoidosis, rheumatoid arthritis
    - 5.2 any congenital or acquired disorders of the eye, or corneal refractive surgery that would preclude successful graft outcome
    - 5.3 retinoblastoma
    - 5.4 malignant tumours of the anterior segment

The Royal College of Ophthalmologists – June 2004
Guidance on the retrieval of human ocular tissue used in transplantation and research

Appendix 4

Enucleation Protocol

(The Royal College of Ophthalmologists 2004)

1. Confirm that consent has been given for the removal of the eyes for transplantation and/or research.
2. Having read the list of contraindications, confirm that there are no obvious reasons to exclude the donor.
3. Collect a sample of the donor's blood, without anticoagulants, for viral and other microbiological testing. Clearly label the blood sample with the donor's name, hospital and date. If the donor has had an infusion of blood, blood products or plasma volume expander greater than 50% of his/her blood volume in the previous 30 days, a blood sample taken before the infusion, where available should be obtained.
4. Open eyelids and irrigate eyes with sterile saline solution to remove debris, mucus and foreign matter. Clean face around eyes, over eyelids, bridge of nose and eyebrows using alcohol wipes. Care should be taken not to touch the cornea with the alcohol wipes during the procedure.
5. Open outer wrapper of instrument pack. Put on sterile gloves and place sterile drapes and eye sheet over donor.
6. Insert lid spectrum and perform peritomy as close to limbus as possible, using fine-toothed forceps and straight strabismus scissors. Tenon's capsule is pushed back by entering each of the four quadrants with the strabismus scissors and performing a blunt dissection.
7. Isolate the lateral (temporal) rectus muscle with a muscle hook, insert artery forceps between the hook and sclera and clamp muscle. Remove muscle hook and cut muscle distal but close to the clamp. Isolate and cut each of the remaining rectus muscles in turn, cutting with the strabismus scissors between the muscle hook and the sclera. There is no particular need to cut the oblique muscles. Care must be taken not to rub the cornea against the spectrum or instruments.
8. Gently lift the eye with the artery forceps. Insert the enucleation scissors from the medial (nasal) side and, keeping the scissors almost vertical, locate the optic nerve by moving the scissors gently from side to side. Still keeping the scissors almost vertical, cut the optic nerve while maintain gentle upward pressure on the eye with the artery forceps. This will ensure that a stump of optic nerve at least 5mm long remains attached to the eye.
9. Once the optic nerve has been severed, gently raise the eye from the orbit, excising residual orbital tissue with the enucleation scissors.
10. Carefully transfer the eye to a plastic eye stand, passing the stump of the optic nerve through the hole in the base of the stand. Secure the eye on the stand by placing a sterile 25 G hypodermic needle through the optic nerve. Place the eye stand and eye (cornea uppermost) on top of a cotton wool ball(or gauze swab) moistened with saline in a sterile pot (a so called moist chamber). The eye must not be immersed in any liquid in the moist chamber.

11. Remove the speculum and repeat the procedure on the other eye.
12. Pack the orbits with cotton wool and, with the aid of eye caps, restore the original appearance of the donor.
13. Clearly label the moist chambers with the donor's name, hospital, date and whether LEFT or RIGHT eye. Complete a UKT Ocular Tissue Donor Information Form.
14. Pack the moist chambers and the blood sample into a UKT eye transport box. Fill a plastic bag with melted water ice. Do not use ice straight from the deep freeze as this could be as cold as -20°C. Do not use Cardice (solid CO_2). Place ice bag into the box. Place completed UKT Ocular Tissue Donor Information Form into the box.
15. Call UKT duty office to notify donor details and collection point.
16. Eye boxes, containing sterile pots, plastic eye stands, plastic bags, eye caps, blood tube and UKT Ocular Tissue Donor Information Forms can be obtained free of charge from UKT by contacting the duty office.

Appendix 5

Stakeholder Groups

Group 1: Palliative care clinical staff

- Registered nurses working in the palliative care environment
- Consultants in palliative medicine

Group 2: Palliative care support staff

- Counsellors
- Religious leaders

Group 3: Other health care professionals

- Transplant coordinators
- Eye bank retrieval team
- Ophthalmic surgeon
- Funeral director

Group 4: Patients and Families

- Palliative care patients
- Bereaved families who have consented to donation
- Recipient of corneas

Appendix 6

A STUDY TO INVESTIGATE THE ROLE AND VALUE OF CORNEAL DONATION IN THE PALLIATIVE CARE SETTING.

(Professional's Information Sheet) *Interview*

My name is Joanne Wells. I am studying towards a Doctorate in Clinical Practice at the University of Southampton. You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

As part of my course I am carrying out a research study into 'corneal donation' within the palliative care setting. I hope to explore the views and opinions of patients, families and health care professionals. The purpose of the study is to investigate whether patients and families wish to be informed about the choice to donate tissue, if so the most appropriate and sensitive way to do this and the implications for health care professionals.

I am an experienced hospice nurse, and would be very grateful if you would consider participating in the study. It would involve your participation in one tape-recorded interview lasting no more than an hour. The interview can take place at your work place or home. What I would like to talk with you about is you thoughts and feelings about corneal donation and your own experiences.

Any information you give will be confidential and will be handled only by the researchers involved (my supervisor and myself). No names will be attached to the information given and tapes and transcripts will be incinerated one year after the study is completed. Any information you provide will be very helpful in exploring whether patients and families wish to be informed of the choice and how they would like it to be discussed.

I realise that it is not always possible for people to participate and you are under no obligation to take part in the study. If you do agree to take part, you are free to refuse to answer any specific questions and may withdraw from the study at any time without giving a reason. If you do decide to take part in the study, you will be given this information sheet to keep and asked to sign a consent form.

If you feel you would like to take part in the study I have included a reply slip and stamped addressed envelope. I would be happy to talk to you further about the study before you decide to participate and answer any questions you may have. My contact numbers are……………………

Thank you.

Appendix 7

REPLY SLIP **(Health Care Professional)**

I……………………………………would/ would not like to take part in the study on corneal donation in palliative care *(Delete as appropriate).*

Place of work……………………………………………………………………..

Grade and Position………………………………………………………………

Contact address…………………………………………………………………..
……………………………………………………………………………………

Telephone number……………………………………………………………….

Appendix 8

A STUDY TO INVESTIGATE THE ROLE AND VALUE OF CORNEAL DONATION IN THE PALLIATIVE CARE SETTING.

(Family Information Sheet)

My name is Joanne Wells. I am studying towards a Doctorate in Clinical Practice at the University of Southampton. You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and family. Please ask if there is anything that is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

As part of my course I am carrying out a research study into ‘corneal donation’ within the hospice setting. I hope to explore the views and opinions of patients, families and health care professionals. One of the purposes of the study is to investigate whether patients and families wish to be informed about the choice to donate tissue and if so the most appropriate and sensitive way to do this. As a family member who has recently been bereaved and also been involved in consenting to donation your participation would be very helpful.

I am an experienced nurse, and would be very grateful if you would consider participating in the study. It would involve your participation in one tape-recorded interview lasting no more than an hour or as long as you feel able to manage. The interview can take place at your home or a place of your choice. What I would like to talk with you about is you thoughts and feelings about corneal donation and your own experiences.

Any information you give will be confidential and will be handled only by the researchers involved (my supervisor and myself). No names will be attached to the information given and tapes and transcripts will be incinerated one year after the study is completed. Any information you provide will be very helpful in exploring whether patients and families wish to be informed of the choice and how they would like it to be discussed.

I realise that this may be a difficult issue to talk about and you are under no obligation to take part in the study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form on the day of the interview. If you decide to take part you are still free to withdraw at any time and without giving a reason.

If you feel you would like to take part in the study, I would be happy to talk to you about it before you decided and answer any questions you may have. My contact numbers are……………………

Thank you.

Appendix 9

Reply Slip (**Family**)

I……………………………………would/ would not like to take part in the study on corneal donation in palliative care *(Delete as appropriate).*

Contact address………………………………………………………………………..
……………………………………………………………………………………

Telephone number……………………………………………………………………..

Appendix 10

A STUDY TO INVESTIGATE THE ROLE AND VALUE OF CORNEAL DONATION IN THE PALLIATIVE CARE SETTING.

(Patient Information Sheet)

My name is Joanne Wells. I am studying towards a Doctorate in Clinical Practice at the University of Southampton. You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and family. Please ask if there is anything that is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

As part of my course I am carrying out a research study into 'corneal donation' within the hospice setting. I hope to explore the views and opinions of patients, families and health care professionals. The purpose of the study is to investigate whether patients and families wish to be informed about the choice to donate corneas and if so the most appropriate and sensitive way to do this.

I am an experienced hospice nurse, and would be very grateful if you would agree to take part in the study. It would involve your participation in one tape-recorded interview lasting no more than an hour or as long as you feel able to manage. The interview can take place at the hospice or your home. What I would like to talk with you about is you thoughts and feelings about corneal donation.

Any information you give will be confidential and will be handled only by the researchers involved (my supervisor and myself). No names will be attached to the information given and tapes and transcripts will be incinerated one year after the study is completed. Any information you provide will be very helpful in exploring whether patients wish to be informed of this choice and how they would like it to be discussed.

I realise that it is not always possible for people to participate and you are under no obligation to take part in the study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form on the day of the interview. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

If you feel you would like to take part in the study, I would be happy to talk to you or your family about it and answer any questions you may have. This can be arranged by the day care leader or by contacting me on ....

Thank you.

Appendix 11

Reply Slip (**Patient**)

I……………………………………would/ would not like to take part in the study on corneal donation in palliative care *(Delete as appropriate).*

Contact address…………………………………………………………………………..

………………………………………………………………………………………

Telephone number……………………………………………………………………..

Appendix 12

A STUDY TO INVESTIGATE THE ROLE AND VALUE OF CORNEAL DONATION IN THE PALLIATIVE CARE SETTING.

(Cornea Recipient's Information Sheet)

My name is Joanne Wells. I am studying towards a Doctorate in Clinical Practice at the University of Southampton. You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and family. Please ask if there is anything that is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

As part of my course I am carrying out a research study into 'corneal donation' within the hospice setting. I hope to explore the views and opinions of patients, families, recipients and health care professionals. One of the purposes of the study is to investigate whether patients and families wish to be informed about the choice to donate tissue and if so the most appropriate and sensitive way to do this. As a cornea recipient your participation would be very helpful as it would give information on the process of receiving corneas and how it has changed your life.

It would involve your participation in one tape-recorded interview lasting no more than an hour or as long as you feel able to manage. The interview can take place at your home or a place of your choice. What I would like to talk with you about is you thoughts and feelings about corneal donation and your own experiences.

Any information you give will be confidential and will be handled only by the researchers involved (my supervisor and myself). No names will be attached to the information given. Tapes and transcripts will be incinerated one year after the study is completed. Any information you provide will be very helpful.

I realise that this may be a difficult issue to talk about and you are under no obligation to take part in the study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form on the day of the interview. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.
If you feel you would like to take part in the study, I would be happy to talk to you about it before you decided and answer any questions you may have. My contact numbers are........................

Thank you.

Appendix 13

Reply Slip (**Corneal Recipient**)

I…………………………………….would/ would not like to take part in the study on corneal donation in palliative care *(Delete as appropriate)*.

Contact address……………………………………………………………………..

…………………………………………………………………………………………

Telephone number………………………………………………………………..

Appendix 14

Interview Confirmation

Dear…………………………..

I am writing to thank you for agreeing to participate in this study and to confirm that your interview will take place:

On……………………………………………………………
Time…………………………………………………………
Venue………………………………………………………..

I look forward to meeting you, and do not hesitate to contact me on………………………if there are any problems.

Thank you again for your participation.

Yours sincerely,

Joanne Wells

Appendix 15

A STUDY TO INVESTIGATE THE ROLE AND VALUE OF CORNEAL DONATION IN THE PALLIATIVE CARE SETTING.

(Professional's Information Sheet) ***Focus Group***

My name is Joanne Wells. I am studying towards a Doctorate in Clinical Practice at the University of Southampton. You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask if there is anything that is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

As part of my course I am carrying out a research study into 'corneal donation' within the palliative care setting. I hope to explore the views and opinions of patients, families and health care professionals. The purpose of the study is to investigate whether patients and families wish to be informed about the choice to donate tissue, if so the most appropriate and sensitive way to do this and the implications for health care professionals.

I am an experienced hospice nurse, and would be very grateful if you would consider participating in the study. It would involve your participation in one tape-recorded focus group lasting no more than an hour. The interview can take place at your work place or home. What I would like to talk with you about is you thoughts and feelings about corneal donation and your own experiences.

Any information you give will be confidential and will be handled only by the researchers involved (my supervisor and myself). No names will be attached to the information given and tapes and transcripts will be incinerated one year after the study is completed. Any information you provide will be very helpful in exploring whether patients and families wish to be informed of the choice and how they would like it to be discussed.

I realise that it is not always possible for people to participate and you are under no obligation to take part in the study. If you do agree to take part, you are free to refuse to answer any specific questions and may withdraw from the study at any time without giving a reason. If you do decide to take part in the study, you will be given this information sheet to keep and asked to sign a consent form.

If you feel you would like to take part in the study I have included a reply slip and stamped addressed envelope. I would be happy to talk to you further about the study before you decide to participate and answer any questions you may have. My contact numbers are.......................

Thank you.

Appendix 16

REPLY SLIP **(Focus Group)**

I……………………………………would/ would not like to take part in the study on corneal donation in palliative care *(Delete as appropriate).*

Place of work…………………………………………………………………………..

Grade and Position………………………………………………………………….

Contact address…………………………………………………………………….
……………………………………………………………………………………

Telephone number…………………………………………………………………..

Appendix 17

Focus Group Confirmation

Dear…………………………..

I am writing to thank you for agreeing to participate in this study and to confirm that your focus group will take place:

On……………………………………………………………
Time…………………………………………………………
Venue………………………………………………………..

I look forward to meeting you, and do not hesitate to contact me on………………………if there are any problems.

Thank you again for your participation.

Yours sincerely,

Joanne Wells

Appendix 18

INTERVIEW GUIDE

Items to be discussed

(This will be altered to suit participants)

Participants:

- understanding of what happens within hospices and their philosophy.
- understanding of tissue donation in palliative care, eg. What can be donated and how and where it is performed.
- own experiences and how it made them feel.
- personal/ professional opinions about patients and families being informed about donation.
- perceptions of the benefit to patients and families being informed.
- concerns about corneal donation.
- views on how, when and by whom patients and families should be informed.
- perceptions of the effects of informing on staff and the palliative care unit.
- understanding of the ethical and moral implications.
- views on the way forward for corneal donation in palliative care.

Appendix 19

FOCUS GROUP SCHEDULE: (HEALTH PROFESSIONALS)

ITEM TYPE	No.	ITEM
Introduction	1	I would like to initially thank you for agreeing to take part in the final stages of this study exploring corneal donation in the hospice setting. To do this I would like you to consider some of the questions I will put to you which relate to some of the findings of the earlier part of the study.
Opening	2	I would like to break the ice, by asking you to introduce yourselves to each other and to briefly share your experience of corneal donation within your practice?
Key	3	What do you feel about palliative care patients or their families being informed about the option of corneal donation?
Key	4	Whose role do you feel it should be to inform?
Key	5	What is currently happening within your clinical areas?
Key	6	What reactions have you seen from patients and families?
Key	7	What reactions have you seen from other staff members?
Key	8	What effect does this have on the donation process?
Transition	9	I would like to now talk about the donation discussion
Key	10	I would like you to comment on the suggestions previous participants have suggested on how and when to inform patients or families (PUT ON FLIP CHART)
KEY	11	What skills do you feel health professionals require to discuss corneal donation?
Transition	12	I just want to talk about the eyes particularly
Key	13	Do you feel the eyes have any particular significance that affects the donation process?
Ending	14	What do you think are the important issues we have discussed today?
	15	Is there anything else anyone would like to add?

Appendix 20

FOCUS GROUP SCHEDULE: BEREAVEMENT AND CHAPLAIN

ITEM TYPE	ITEM NO.	ITEM
Introduction	1	I would like to initially thank you for agreeing to take part in the final stages of this study exploring corneal donation in the hospice. To do this I would like you to consider some of the questions I will put to you which relate to some of the findings of the earlier part of the study.
Opening	2	I would like to break the ice, by asking you to introduce yourselves to each other and to briefly share your understanding of the organ and tissue donation in the hospice. Give them a brief overview of corneal donation.
Key	3	Have any of you been involved in discussion around donation within the hospice. If so please tell us about it?
Key	4	What are your initial thought about hospice patients or their families being informed about the option of corneal donation?
Key	5	Do you feel that the hospice being involved and facilitating corneal donation interferes with attempting to enable a dignified peaceful death?
Key	6	Do you feel that patients or families should be informed about the option of corneal donation?
Key	7	Do you feel that everyone should be informed of the option?
Key	8	Do any of you have any thoughts on when would be appropriate times to have the discussion?
Key	9	What effects could informing patients or families about donation have on them. Both before and after the person has died. Positive and negative?
Key	10	These are some of the key issues that have been raised on various occasions through out the interviews could you tell me what you think? 'Patients and families have already been through enough, this is just something extra to burden them with' 'This is something positive that can come out of a distressing situation' 'Eyes are the windows to the soul' 'People want to keep their eyes to see in the next world'
Key	11	What could be the effects on bereavement?

Key	12	Would you feel confident to talk about corneal donation?
Ending	13	What do you think are the important issues we have discussed today?
	14	Is there anything else anyone would like to add?

Appendix 21

Line-by-Line Coding

Nurse A

Q.5. What is your understanding of what palliative care patients can donate?

A/ They can donate their corneas, um, I can't remember what else. Is it their heart valves? I know they can ask for their bodies to be used for medical science and things like that. Um, I can't remember what else it is.

Donate cornea.
Can't remember.
Bodies for science

Q.6. Um, you spoke about corneas, which is predominately what people can donate, do you feel that the eyes have any particular issues for people?

A/ Yes, a lot. Definitely, because the eyes are part of what the person is and you get relatives talking about how they love their husband and wife, and they do say they have got lovely eyes or can you look after their eyes. They say their eyes are this or their eyes are that. There is a lot connected with it. Um, can you make sure their eyes are shut if they are sleeping? It seems to be something that weighs heavily on relatives and you know um, and friends, just anybody really, about how the eyes are connected to the actual person and what the show and what they tell. It is quite far reaching.

Part of the body.
Love their eyes.
Got lovely eyes
Eyes are this or that.
Lot connected to eyes
Weigh heavily on eyes.
Are connected to person
What they show and tell.
Quite far reaching.

Q.7. Thank you, What are your views

A/ Um, I feel that I ought to be as a professional, I ought to, I ought to be impartial about it and I do understand the necessity for having corneal donation. But it is very difficult, because if you are looking after somebody, and to get quite connected to them and close to the family as well, it is a difficult subject to broach about how you go about asking whether they would think about it. Because the eyes do say a lot about somebody, and I have always been a bit squeamish about eyes anyway. I think a lot of people are the same.

Ought to be professional
Ought to be impartial.
Understand necessity
Difficult as looking after them.
Get connected.
Difficult subject to broach
Eyes say a lot.
Squeamish about eyes

Appendix 22

NHS

South East Multi-centre Research Ethics Committee

Chairman of the South East MREC – Dr J Lamberty FRCA

Room 76, B Block
40 Eastbourne Terrace
London W2 3QR

Tel: 01227 831 662
Fax: 01227 831 662
Email: jane-martin@ttmrec.fsnet.co.uk

Mrs J Wells
6 Romney Close
Ashford
Middlesex TW15 IEE

16th September 2002

Dear Mrs Wells

MREC 02/01/72 A study to investigate the role and value of corneal donation in the palliative care setting.

Protocol – version 1
Subject information sheet – version 2
Reply slip (patient) – version 1
Professionals information sheet (interview) – version 1
Consent form for professionals – version 1
Family information sheet – version 1
Reply slip (family) – version 1
Interview Guide – version 1
Cornea Recipient's Information Sheet – version 1
Reply slip (corneal recipient) – version 1
Letter to subject re interview/focus group – version 1
Consent form – version 1
Mrs Wells curriculum vitae

The Vice-Chairman of the South East MREC has considered the amendments submitted in response to the Committee's earlier review of your application on 14th August 2002 as set out in our letter dated 21st August 2002.

The Vice-Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set down below. A record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the use of an existing database collected for previous research or other purposes with subsequent patient contact patient. **For this reason you are asked to read carefully the sections concerning LREC involvement and local NHS management set out below as there are specific requirement involved when undertaking such research.**

The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees

Appendix 23

CONSENT FORM

A Study to Investigate the Role and Value of Corneal Donation in the Palliative Care Setting.

Joanne Wells

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the above study ☐

Name of Participant Date Signature

Researcher Date Signature

1 for participant, 1 for researcher, 1 to be kept with hospital notes (If Patient)