Hope for a peaceful death and organ donation

Holly Louise Northam

RN, RM, Master of Critical Care Nursing (UC)

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‘These three remain: faith, hope and love, and the greatest of these is love’

(1 Corinthians, 13:13).
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## Abbreviations

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<tr>
<td>ANZICS</td>
<td>Australia and New Zealand Intensive Care Society</td>
</tr>
<tr>
<td>AODR</td>
<td>Australian Organ Donation Register</td>
</tr>
<tr>
<td>ACCCN</td>
<td>Australian College of Critical Care Nurses</td>
</tr>
<tr>
<td>ATCA</td>
<td>Australasian Transplant Coordinators Association</td>
</tr>
<tr>
<td>DBD</td>
<td>Donation after Brain Death</td>
</tr>
<tr>
<td>DCD</td>
<td>Donation after Cardiac Death</td>
</tr>
<tr>
<td>DO</td>
<td>Designated Officer</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency Department</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>NODC</td>
<td>National Organ Donation Collaborative</td>
</tr>
<tr>
<td>OPO</td>
<td>Organ Procurement Organisation</td>
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<tr>
<td>TSANZ</td>
<td>Transplantation Society of Australia and New Zealand</td>
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Glossary

Death

The Australian Law Reform Commission (1977) defined death as the a) irreversible cessation of all function of the brain of the person or b) irreversible cessation of circulation of blood in the body of the person.

Deep hope

This idea is drawn from palliative care literature. Deep hope is defined as: a layer of hope that underlies this experience and may continue to exist, or even thrive, during a time when the patient[and their family] has very few ‘somethings’ left to hope for (Coulehan, 2011, p. 144).

Empathic neutrality

Patton (2002) uses this term to describe an interview technique whereby the interviewer uses a non-judgemental approach which demonstrates attentiveness, ‘openness, sensitivity, respect, awareness, and responsiveness’ (p. 40) to establish a vicarious understanding of the participant experience.

Family

Family was defined as those that self-select as ‘family’ of the deceased, that are recognised as family in the naturalistic setting, and were involved in the family decision-making process. Consistent with real-world experiences, family may include people without a legally recognised relationship. Depending on jurisdictional clinical practices, these people may or may not be involved in the formal decision-making action of providing written consent for organ donation.

Hope

‘Hope Theory’ was defined by Snyder (2002) as ‘the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways’ (p. 249).

Moral Discernment

A concept discussed by Christians (2005) that sees an unfolding alignment of a common moral understanding which takes place in the interaction and collaboration of the researcher with the researched. Christians (2005) argues this is ‘a radical alternative to the individualism of modernity’ (p.155) and is an idea that aligns with the philosophical stance of this study.

Trust

The definition for trust used in this study combines rational and relational trust and is defined by Barber (1983) as ‘social learned and social confirmed expectations that people have of each other, of the organisations and institutions in which they live, and the natural and moral social orders, that set the fundamental understandings of their lives’ (p. 28).
Abstract

The therapeutic, social and economic benefits of organ transplantation are irrefutable; however, organ shortages contribute to avoidable patient deaths and burgeoning health care costs. This problem can be addressed by increasing family consent to deceased organ donation. There are high levels of community support for deceased organ donation in Australia and yet, almost fifty percent of families decline the request to donate. Increasing the number of families who agree to deceased organ donation is key to increasing national and international transplantation rates.

The purpose of this study was to identify the major factors that influence a family to agree or decline deceased organ donation during the process of decision-making. The aims of the study were three-fold: to identify the key stages and the major influencers’ in the decision-making process; to determine if hope, deep hope and trust played a role in the decision, and to explore families’ perceptions of their decision-making experience.

The study utilised an exploratory case study approach to examine the family decision-making process of deceased organ donation. Following ethics approval, recruitment was conducted utilising a qualitative purposive snowball strategy across Australia. A pilot study was conducted to test the study procedures prior to the main data collection, and 22 participants who had been involved in a deceased organ donation decision from nine families were interviewed. In five deaths family members had agreed to organ donation, and in four deaths the family declined. A theoretical framework based on the Precaution Adoption Process Model of decision-making was applied to propose trust, hope and deep hope underpin family organ donation decisions.
Thematic analysis was conducted and three key themes comprising ‘In the fog drowning’, ‘Harvesting humanity’, and ‘It’s all up to Mum’ were revealed. The study found women, and in particular mothers, played a significant role in organ donation decision-making, and that the decision-making is bounded by family needs of trust, hope and deep hope across the continuum of time. It also found families who had their trust, hope and deep hope needs met expressed satisfaction about their decision-making experience and agreed to organ donation. Some families perceived that organ donation was a sacrifice that was too great to endure, even if the deceased had previously indicated intent to donate, and therefore declined donation.

This study found that families’ ideas of a peaceful death and organ donation are not mutually exclusive. It concludes that when decision-makers’ trust and deep hope needs are met they are more willing to agree to donation. This study recommends that the idea of a ‘right’ to a peaceful death should be aligned with deceased organ donation practices and normalised.
Chapter 1: Introduction

1 Introduction

‘Don’t take your organs to heaven, heaven knows we need them here’ is a call to action heard in the community that challenges people to agree to deceased organ donation for transplantation. There is an urgent need to increase organ donation rates in Australia and throughout the world as the numbers of patients who will die without a transplant continues to rise (Cass et al., 2010; Rudge, Matesanz, Delmonico & Chapman, 2012; World Health Organization (WHO), 2010). Some countries such as Spain have achieved a level of self-sufficiency whereby children in renal failure receive a transplant before needing dialysis (Miranda, Vilsrdell & Grinyo, 2003), and there is evidence that dialysis rates are decreasing as patient transplant needs are being addressed (National Transplant Organisation (ONT), 2013). The tantalising hope offered by a transplant to patients on waiting lists is countered by the sense of despair expressed by families when death intervenes before a donated organ is offered. The human face of this suffering is revealed, and the effect of organ shortage is highlighted in the public conversation. For example, Australian media reported a grieving parent publically proposed that his son’s death while waiting for a liver transplant was preventable (Morrison, 2014).

The therapeutic, social and economic benefits of transplantation are irrefutable; however, the complex dynamics behind organ shortage and behaviours relating to transparency (Hyde, 2012; Rady, McGregor & Verheijde, 2012), equity (WHO, 2010), morality (Fox & Swazey, 2013; Shimazono, 2007) and resource and legal influences affect their availability. Live organ donation is one strategy to address the shortage of some organs, but poses risks for donors, which
is balanced against the recipient need (National Health & Medical Research Council (NHMRC), 2007). In Australia, deceased organ donation is represented as an altruistic gift, given without expectation of acknowledgement or reward (NHMRC, 2007) using a regulatory framework consistent with the WHO (2010) principles for deceased organ donation. Increasing rates of family agreement to deceased organ donation requests is fundamental to increasing national and international transplantation rates (Domínguez-Gil et al., 2010; Vincent & Logan, 2012; WHO, 2010) and is a strategic priority for the Australian Organ & Tissue Donation Authority (Organ & Tissue Authority, 2012).

In Australia, fewer than 60% of families agree to donate their deceased family members’ organs (Marck, et al., 2014; Australian Organ and Tissue Authority, 2014). This is despite 1) public polling indicating that around 80% of Australians are willing to donate their own organs (Woolcott, 2012, p. 89); 2) the registration of approximately one quarter of the Australian population on the Australian Organ Donor Register (AODR) (Department of Human Services, 2014), and 3) a media that promotes the benefits of organ donation (Milligan, Winch & Adams, 2012; Morrison, 2014; Oberender, 2011). The Australian refusal rate remains substantially higher than international benchmark comparisons with countries such as Spain, where the refusal rate is 15% (Domínguez-Gil et al., 2010), the United States, approximately 25% (Siminoff, Agyemang & Traino, 2013). The United Kingdom has the highest refusal rate in Europe (Walker, Broderick & Sque, 2013). Studies reveal it has a consent rate of 64% for donation after brain death (DBD) and 50% for donation after circulatory death (DCD) (Walker, et al., 2013).
There is little written about the stories of donors, their families or their contribution to transplantation therapy throughout the years in which deceased donor organ transplantation was first trialled, and as it became an accepted therapy (Holtcamp, 2002). There is limited information about the identity of the early donors or their families and for the most part, they remain anonymous (Holtcamp, 2002; Pittman, 1985). Even less is known about families that experienced a loved one’s death and made an organ donation decision in circumstances where donation did not or could not proceed, and the implications of those experiences for their bereavement and ongoing views on organ donation. Most studies of donor families have been limited by small sample sizes, and families that were overtly positive, and agreed to donation and were happy to share their views; however, ‘a vast majority of donor families, as well as those that chose not to donate, have often remained silent’ (Holtcamp, 2002, p. xxv). According to Holtcamp, ‘it is this silent majority that could contribute much to our understanding’ (p. xxv).

This study will explore the family experience of deceased organ donation decision-making. This chapter introduces the background, the purpose and aims of the study, and its significance and implications. An overview of the chosen methodology and theoretical framework, plus the terminology that will be used in this study will be presented. The decision-making context and consequences for families asked to donate their deceased relatives’ organs will also be described. The assumptions and limitations of this study and my position as the researcher are explained, and finally the chapter concludes with an outline of the thesis.
1.1 Background to the study

1.1.1 The imperative of organ transplantation

Australia is experiencing an epidemic of diabetes and renal failure, and the cumulative cost of renal replacement therapies between 2009 and 2020 is expected to reach approximately $12 billion (Cass et al., 2010). Transplantation is the most effective treatment for patients suffering end stage organ failure and provides significant social and economic benefits by reducing the cost of patient care (Cass et al., 2010). Increasing rates of organ donation for transplantation is therefore a national priority (Rudd, Roxon & McLucus, 2008) and is linked to the prevention and management of complex chronic diseases. In most circumstances the capacity to provide transplantation is dependent on the altruism of families asked to donate their deceased relatives’ organs (Siminoff, Arnold & Caplan, 1996).

In 2012, Australia had a population of 22.7 million people with 147,089 deaths recorded (Australian Bureau of Statistics (ABS, 2014). Also, in 2012, 342 deceased people donated their organs in Australia (Australia and New Zealand Organ Donation Registry (ANZOD), 2014) with 48% of the 710 families asked to donate the organs of their deceased relatives (Organ & Tissue Authority, 2014). Due to the unexpected nature of the deaths, 43% required coronial approval to allow organ donation to proceed (ANZOD, 2014). In that year, Australia had 15.5 donors per million population (dpmp, the measure used for international comparisons and benchmarking of organ donation) which is less than half the donation rate of many countries, such as Spain (35 dpmp), Croatia (35 dpmp) and Belgium (30 dpmp) (Gomez, Perez, & Manyalich, 2014). Australia’s donation rate is currently ranked 22nd in the world using international benchmarking, placing it behind countries such as France, Norway, Italy, UK, Ireland, Uruguay, Poland and
Argentina (Gomez, Perez, & Manyalich, 2014), and within the lowest third of the Organisation for Economic Cooperation (OECD) countries (Komesaroff, 2012).

There is a clear imperative for governments to increase organ donation rates to save lives and to limit the suffering and burgeoning health care costs associated with organ failure. This international problem has forced the World Health Organisation to take measures to limit unethical practices such as human trafficking, transplantation tourism and the organ trade (WHO, 2010) for people desperate to receive a transplant. Governments are required to find ways of meeting the transplantation needs of their own populations (WHO, 2010).

The contemporary context of this study is historically situated in a period of great change in the delivery of Australian organ and tissue donation and transplantation services. Significant effort and cost has been expended over a prolonged period in attempts to increase the Australian organ donation rate, which has included reviews, reports, a proliferation of organisations designed to promote deceased organ donation, communications strategies, establishment of an organ donor register in 2000 and a taskforce into organ donation (National Clinical Task Force on Organ and Tissue Donation, 2008). This study follows the National Organ Donation Collaborative, which was based on the US Breakthrough Collaborative Methodology and trialled in 22 Australian hospitals from 2006 to 2009 (Thomas, Milnes & Komasaroff, 2009). It saw hospital teams comprising managers, emergency and intensive care consultants, and intensive care nurses implement quality improvement processes in organ donation. In this way, the initiative contributed to the highest level of organ donation in over 10 years (Thomas et al., 2009).
Legislation was passed in 2008 to establish the Organ & Tissue Authority in 2009 (Rudd, Roxon, & McLucus 2008; Rudge et al., 2012). Funding of over $150 million dollars was allocated over a four-year period to support this initiative (Komesaroff, 2012; Oberender, 2011). This new national organisation was heralded with significant political and media interest as a national bipartisan approach to address the organ shortage (Oberender, 2011) and its success has been scrutinised by governments, health care and policy analysts, organisational leaders, the media and international observers. Organisational changes have included the employment of specialist doctors and nurses in hospitals to optimise deceased organ donation (Oberender, 2011). These strategies have led to an increased organ donation rate in Australia (Nash, 2015).

1.1.2 Legislative context of deceased organ donation decision-making

The legal frameworks that regulate organ donation decision-making and practices vary internationally. It is argued that a presumed consent legislative framework, known as opt out (Fabre, Murphy & Matesanz, 2010) is the most effective means of increasing rates of organ donation (Bird & Harris, 2010). This legislative framework is present in some countries who report high rates or organ donation such as Spain and Belgium (Fabre, et al., 2010). Proponents argue that the donation rates are high in countries with presumed consent legislation, where it is assumed that if a deceased person has not registered a refusal they would wish to donate, thereby enabling their subsequent organ donation even in cases of family objection (Morrison, 2014). However, Spain has no organ donor register as do some other countries and Fabre et al. (2010) argue that the high rates of donation in Spain can be attributed to the skill of the hospital staff and the organisational structures that support organ donation practices. According to Fabre et al.
In Australia, each of the eight states and territories has a different deceased organ donation consent legislative framework (Lawrence, 2004). Four jurisdictions have legislation which is similar or based on the presumed consent legislation that underpins the Spanish legislative model (Lawrence, 2004). Despite these varied legislative settings, an opt-in model of organ donation consent is utilised, whereby members of the general public register their consent to become an organ donor in the event of their death, and donation organisations still require the explicit consent from either the deceased or the family (Naffine, Richards, de-Lacey, Braunack-Mayer & Rogers, 2012). The AODR was established in 2000 as a register of donation intent decisions, but these designations were not accepted as legally valid consent decisions until 2005, when legislation supporting the AODR was strengthened to meet jurisdictional legislative requirements for consent decisions (Australia and New Zealand Intensive Care Society (ANZICS), 2013, p. 36), thereby enabling the autonomous wishes of the deceased to be accessed by qualified health professionals at the time of death.

A family is able to over-ride a deceased registered wish to donate, but is unable to over-ride a deceased refusal to donate in contemporary clinical practice, and donation can only proceed once a designated officer (DO) with legal authority for the hospital provides approval (ANZICS, 2013). The DO must be satisfied that the death, plus requirements for consent and clinical processes have met legal requirements including coronial authorisation to proceed if a death is reportable under the relevant jurisdiction’s Coroners Act (Neate et al., 2013). In 2012,
coronial approval preceded 43% of organ donations (ANZDATA, 2013, p. 3). Unlike in some other countries, there is no obligation for the coroner to account for a decision to delay or decline permission for donation to proceed, a factor that may create an additional barrier to donation (Shafer et al., 1994). Therefore, it is argued that organ donation is reduced because practices in clinical settings use negative interpretations of the law regarding consent for deceased organ donation (Naffine et al., 2012).

Public pressure around the idea that Spain’s success in donation is caused by a presumed consent or opt-out legislative framework has resulted in several Australian jurisdictional government inquiries and reports (Delriviere & Boronovskis, 2011; New South Wales, 2012; Queensland, 2009; Victorian Government, 2012) that examined strategies for increasing organ donation, and included the possibility of legislative change to a presumed consent legal framework. All governments ultimately concluded that legislation was not obstructing Australia from achieving donation rates equivalent to Spain and comparable countries (New South Wales, 2012; Queensland, 2009; Victorian Government, 2012). These findings were also supported by an analysis of the potential for organ donation in Australia (Bendorf, Kerridge, Kelly, Pussell & Guash, 2012) and commentary (Komesaroff, 2012). Arguments posed by Spanish researchers such as Dominguez-Gil et al. (2010) and others (Fabre et al., 2010; Rudge et al., 2012) are that regardless of whether the country has opt-in or opt-out legislation, deceased organ donation consent is dependent on organisational support and health care professional skill in identifying deceased donors and supporting families in their decision experience.
The debate about the right of families to over-ride the express wishes of their loved ones continues to ‘rage’ in the Australian conversation. An example is the advertised DonateLife Week debate between politicians and celebrities: My decision my choice (Organ Donation and Transplant Foundation of Western Australia (2013). Ethicist Katrina Bramstedt (2013) argues that even a small number of families who over-ride deceased individuals’ decisions to donate has significant implications: as many as 50 patients that could benefit from donation might be affected by a single such family decision. The individual decision to donate, if registered on the AODR, is effectively an advance directive and Bramstedt’s argument is that the decision to ignore that has implications for the donor who, when alive, clearly stipulated their wishes. This argument runs counter to that of the families asked to donate, who believe their role remains as gatekeeper to the protection of their loved one (Bramstedt, 2013).

1.1.3 Public discourse regarding deceased organ donation decision-making

Although the Australian media is generally supportive of organ donation (Transplant Australia, 2014; Woolcott, 2012), publishing stories about the benefits of transplantation (Gates, 2014) and the risks to patients that are waiting (Auerback, 2014; Hansen, 2013), the public has little insight into the experience of families who go through the decision-making process of deceased organ donation, or the potential ramifications of the donation decision on the family (Holtkamp, 2002). Sque, Long, Payne and Allardyce (2008), in a study of families that declined organ donation, found that some participants felt guilty, were sensitive about being judged critically for making a decision to decline donation and expressed relief to know that others had made similar decisions. MacDonald, Liben, Carnevale and Cohen (2008) described similar findings about a mother that initially offered donation as a gift, and expressed regret and distress
when she and her husband made a decision to withdraw the donation because of family distress caused by delays in the donation process.

The public discourse in Australia is silent on the potential psychosocial harm that may be suffered by bereaved families who decline donation which may be caused by community pressure to donate and a view that the decision to decline organ donation is selfish. Social pressures can also affect bereaved families who allow donations to go ahead. For example, they can experience distress through the approbation of friends and extended family who judge their decision to donate their loved one’s organs as ‘cruel’ (Manzari, Mohammadi, Heydari, Sharbaf, Azizi & Khalegh, 2012, p. 661). Further, some family members’ bereavement is complicated by guilt associated with their belief that they should have asked staff about organ donation at the time of their loved one’s death and done more to ensure their loved one’s donation wishes were honoured (ANZICS, 2013, p. 30). Indeed, Pelletier (1992) identified that one of the greatest stressors for families was not being asked to make or consider a deceased organ donation decision on behalf of their family member.

Little compassion is evident in the public discourse for families who decline organ donation and there has been little interest in their reasons. This phenomenon is apparent in online forums calling for the removal of the family influence from the decision (Cahill-Lambert, 2013). In contrast, health care professionals who are directly involved in caring for the dying patient and their family, and who have knowledge of the organ donation process, appear more cautious and have a more compassionate view of the decision implications for families, and the sensitivity of the situation (ANZICS, 2013; Sque, Long, Payne & Allardyce, 2008).
In addition, an undercurrent of mistrust about deceased organ donation has been detected in Australian views and understandings of deceased organ donation (Komesaroff, 2012). There is evidence that those that do not designate themselves as donors may be responding to a fear that organ donation could hasten or bring about their death (Hyde, Wihardjo & White, 2012; Woolcott, 2012). A distrust of hospitals and doctors has been identified in minority groups (Brown, Foulkrod, Dworaczk, & Thompson, 2010), which is pertinent to the multicultural context of death and deceased organ donation decision-making in Australian hospitals (Bloomer & Al-Mutair, 2013), and has led to the delivery of targeted information for these groups (Nash & Payne, 2014; Wood, 2012). Concerns about the organ trade, equity in organ allocation and the perceived worthiness of recipients also affect public attitudes (Hyde, et al, 2012). These findings are consistent with those from the US where deep distrust of medical institutions and staff involved in organ donation are cited as reasons for not wanting to sign donor cards or donate organs (Morgan, Harrison, Afifi, Long, & Stephenson, 2008; Siminoff & Arnold, 1999).

1.1.4 Deceased organ donation decision-making communications strategies

In Australia, a $13.4 million ongoing education and awareness campaign to increase organ donation commenced in 2010 and was evaluated using a quantitative tracking study (Woolcott, 2012, p. 1). This campaign was managed by the Organ and Tissue Authority which had been established in 2009. The campaign encouraged families to be aware of, and discuss, their loved one’s donation wishes at death (Woolcott, 2012, p. 11), and it encourages the use of the AODR as a way of ensuring the donation wishes are known and honoured by the family (Donatelife, 2015). Strategies to encourage increased levels of donation have tended to focus on utilising ‘nudge’ tactics (Fischer & Lotz, 2014). The campaigns have appealed to individuals’
hope to help others and involve communication practices that provide little detail about the
donation process. It is possible that some may interpret these practices as coercive which is
possible when decision-makers receive insufficient information to enable informed consent
(Milligan, et al., 2012). The role of individual autonomy and the family desire to honour a
deceased loved one’s wishes has been found to be one of the most important factors influencing
families to agree to donate (Siminoff, Gordon, Hewlett & Arnold, 2001; Thomas et al., 2009;
Tymstra, Heynik, Pruim & Sloff, 1992) and underpins campaign messages. Conversely, this
form of promotion is questioned within the health and legal professions with the argument that
such promotion could be viewed as coercive and paternalistic in that it fails to assure that the
legal requirements for informed consent in medical decision-making are met, such as ensuring
the competence of the decision-maker, full disclosure of the process and its implications, and
understanding the risks and benefits without coercion (Milligan et al., 2012; Verheijde & Rady,
2012). Further, the effectiveness of the campaign has been questioned on the basis that
individuals may be advising their families to refuse donation instead of families telling their
family members their wish to donate (Verble & Worth, 2012).

A benchmarking survey to measure the effect of the education and awareness campaign
found that 35% of respondents would prefer deceased organ donation decision-making to be
made on their behalf by their family members at the time of their death, and 31% were concerned
that they would not be dead before organ donation (Woolcott, 2012, p. 102). Distrust of the
practices involving the determination of death and organ donation may be a significant influence
in individuals wanting their families to make organ donation decisions on their behalf, rather
than the less salient fear of discussing death with their family, which was suggested by the
authors (Woolcott, et al., 2012). Significantly, gender appears to play a role in organ donation decision-making with Woolcott et al. finding that 68% of women had made a donation decision compared with 59% of males (p. 86). Public discussion about organ donation and the need to increase Australian organ donation rates has created a range of expectations about organ donation at death. It is possible these expectations are not being met, so it is timely to examine the ‘consumers’ (bereaved family) perspective.

1.1.5 The request for deceased organ donation

Studies have found that approaching a family to request organ donation is viewed as one of the most difficult tasks required of intensive care professionals (Kiss, Bischoff, Kainz & Kesselring, 2007). In the UK, collaborative approaches to the request to donate were trialled in a randomised controlled study (ACRE Trial Collaborators, 2009) in which donor coordinators worked with intensivists to request donation. However, results were inconclusive due to inconsistencies in the selection of sites and an inability to standardise aspects of the trial (Vincent & Logan, 2012). Spain and many of the countries that have adopted the Spanish Model utilise a structured approach using purpose-trained medical coordinators who request organ donation from the family (Rodriguez-Arias, Wright, & Paredes, 2010).

The use of an opt-in legislative model (first person authorisation) in some states in the US involves a presumptive approach towards the family if the deceased had previously registered themselves as a donor (Siminoff et al., 2013). The process is structured such that when a clinical trigger of impending death is met, a referral is made by the treating health care team to the Organ Procurement Organisation (OPO) and a specialist requestor then approaches the
family. The family are told that their relative is a donor and that to honour their wishes the
donation will proceed (Siminoff et al., 2013). In some situations the donation continues despite
family refusal (Siminoff et al., 2013). These practices remain controversial and recent
commentary questions the ethics involved in their practice and efficacy (Verheijde & Rady,
2012). However, others argue that the policy is proving effective (Traino & Siminoff, 2013).
Until recently, countries such as Australia and New Zealand have used a model in which the
specialist caring for the deceased also requests organ donation from the family (ANZICS, 2013).
New models of requesting organ donation utilising ‘designated requestors’ are currently being
trialled in some areas in Australia (NSW Health, 2014). Further, education programmes to teach
doctors and nurses the best way of requesting organ donation have been introduced throughout
Australia as part of the Organ Donation Authority, Second Strategic Priority for 2012–13 (ODA, 2012).

1.1.6 Defining the clinical circumstances of deceased organ donation decisions

The feasibility of donating organs for transplantation is restricted to clinical
circumstances where critical care expertise is available to maintain a dying or deceased patient’s
organ function until death is proven, medical and recipient suitability is confirmed and specialist
teams are ready to conduct the surgery (Australasian Transplant Coordinators Association
(ATCA), 2008). Grieving and unprepared families are required to quickly come to terms with
their impending loss and accept that their loved one’s death is inevitable (Pearson, Hickson,
Greenwood, Robertson-Malt & Tucker, 1998), often in unexpected and traumatic circumstances
(Pelletier, 1992). Families may find it particularly difficult to accept a diagnosis of brain death
(Franz et al., 1997), especially where visual evidence of devastating injury might be hidden, and
the family is reliant on trusting medical advice that their loved one has died (Pelletier, 1992). Further, it is presumed that to agree to donation, the family needs to be aware their decision may make the difference between the life and death of another patient awaiting transplantation, because the decision is based on no other reward than altruism (NHMRC, 2007, p. 3).

In Australia, the scenarios that lead to families being asked to donate their dying or deceased family member’s organs generally only occur in the critical care environments of intensive care units (ICUs) and emergency departments (ANZICS, 2013). Even in these settings ventilatory and circulatory support can only be instituted and maintained until physiological collapse occurs, a decision to limit suffering by withdrawing mechanical ventilation is made (ANZICS, 2014) or death is revealed (ANZICS, 2013). It is at this time that the possibility of organ donation may be presented to a family by the doctor treating the patient (ANZICS, 2013). It is a legal and ethical requirement that the possibility of conflict of interest is minimised, so that a doctor caring for a dying or deceased potential organ donor cannot ask the patient’s family to donate while at the same time providing treatment to a potential recipient of that patient’s organs (ANZICS, 2013). When a family in Australia is asked to donate their family member’s organs, the question is positioned in the context of death defined as either ‘irreversible cessation of all function of the person’s brain, or irreversible cessation of circulation of blood in the person’s body (ANZICS, 2013, p. 41). The examinations that confirm death are conducted by doctors using either circulatory or neurological criteria that require different clinical practices.

Organ donation after confirmed circulatory death is termed organ donation after cardiac death or DCD (ANZICS, 2013, p. 47). The criteria used by the doctor to determine death
includes ‘immobility; apnoea, absent skin perfusion, absence of circulation for a minimum of two minutes measured by feeling the pulse, or by monitoring the intra-arterial pressure’ (ANZICS, 2013, p. 52). Organ donation following death diagnosed using these non heart beating criteria has a different range of implications for family experiences of observing the death and separating from their loved one’s body, than those surrounding brain death, which is determined using neurological criteria while the heart continues to beat. DCD is classified using internationally recognised nomenclature and in Australia, Maastricht III DCD, otherwise known as ‘controlled’ DCD, is utilised, requiring the donation decision to be made before an expected death following the planned cessation of futile treatment (ANZICS, 2013). This decision is complicated because the patient must die within a specified period of 60–90 minutes following the removal of life-sustaining interventions, or the patient cannot donate organs. If death occurs within the required time frame, the deceased is transferred from the ICU to the operating theatre within minutes of death for organ donation surgery. In some circumstances, logistics may require the dying patient to be moved to the operating theatre in anticipation of the removal of life-sustaining interventions and death. Both circumstances have significant implications for the family experience of their loved one’s dying and death.

When organ donation occurs after confirmed brain death (DBD), specialist doctors are required to use specific criteria to confirm the patient is in an unresponsive coma with absent brainstem reflexes and absent respiratory centre function, which together demonstrate irreversible cessation of all function of the brain, which is confirmation of death (ANZICS, 2013, p. 17). Either before or after testing, the family is made aware that proof of death will require all treatments including ventilation to be ceased because the patient has died. However, these
interventions are delayed until organ donation surgery if the family agrees to donation. Similarly, for DCD the family will make a decision while their loved one’s circulation is maintained using mechanical ventilation and while their heart continues to beat. In contrast to DBD, this decision is made having been informed of the death before ventilatory support is removed. A significant difference between families who witness DCD processes and those who witness DBD is that the latter requires the family to farewell their deceased loved one while the heart continues to beat, because perfusion is maintained until organ retrieval to improve transplant outcomes. In DCD the body is taken from the family after heart beat and circulation have ceased.

The practical requirements for these processes are complex and cannot be instituted until medical suitability, legal and clinical requirements have been met, which, depending on the location of the patient and the circumstances of the death and donation, may take many hours (NHMRC, 2007). Further, as previously mentioned, in situations of DCD there is no certainty that the patient will die in a timeframe that allows organ donation to proceed, which further complicates the request for donation by the treating doctor, the family response and logistics. In 2012, the median time between the declaration of brain death and the donation surgery and aortic cross clamp was 18.5 hours (ANZOD, 2013). The organs, which in Australian clinical practice comprise the heart, lungs, liver, kidneys, pancreas and intestines (ANZOD, 2015), can only remain viable if circulation is maintained up to the time that the donation surgical team is actually in place and ready to operate at the hospital where the deceased patient is located (ATCA, 2008). This is the crux of the procedural difficulty of successful organ donation for transplantation. In Australia, donation teams comprise specialist surgeons, organ perfusionists and transplant coordinator nurses who collaborate with hospital staff where the deceased patient
is located to complete the organ donation surgery and transfer the donated organs. The team will then return to centres where patients awaiting transplant are being readied for surgery, which may involve flights covering hundreds of kilometres or more. The same surgical team will often perform the surgery to implant the donated organs in recipients.

Time is strictly limited in these situations because once circulation has ceased to the organs, even with preservation techniques such as cooling and specialised solutions, the organs’ cellular function is dying: organs will not function in a recipient after prolonged ischemic times (Banner et al., 2008). For example, in the case of a donated heart, once circulation has ceased, it must be recovered, transferred and implanted in the chest of a recipient with circulation restored within a maximum of four to five hours to be effective (Russo et al., 2007). This differs from circumstances of tissue donation, which may include cornea, skin, musculoskeletal and heart valve tissue able to retain cellular function for up to 24 hours following circulatory arrest (NHMRC, 2007, p. 10) and even after a deceased patient has spent many hours in a mortuary.

These levels of complexity make it difficult for hospital staff to understand the requirements of organ donation especially given most staff have never been exposed to the situation. Many hospitals will only have one to two deceased organ donors a year and smaller hospitals may never be exposed to organ donation (ANZOD, 2013). The request for organ donation is generally only encountered by families who have loved ones that die as a result of severe neurological damage in large regional or tertiary ICUs (ANZOD, 2013). A high level of community awareness about the need for organ donation means that questions about deceased organ donation and offers of donation may be asked by family members of health professionals.
at any time a loved one is dying or dead in the vast array of locations where death occurs in Australia. Given the small number of organ donors, in most circumstances staff who may be asked questions about deceased organ donation could be uncertain about how to respond, having never encountered the clinical situation of organ donation, and may therefore be unfamiliar with its requirements, or those of tissue donation.

1.1.7 Health care professionals and deceased organ donation decisions

The professional relationships between the health care team, the patient and their family are known to have the potential to influence family decision-making in various ways. The moral and intellectual dissonance that is known to alarm some health care professionals who care for dying and deceased patients that are potential organ donors, and their families (Pearson & Zurynski, 1995), is believed to be influenced by several factors including a fear that asking for donation and making a donation decision may cause harm to the family (Morton & Leonard, 1979). Conversely, Cleiren and van Zoelen (2002) found that family bereavement distress was more likely influenced by dissatisfaction with their experiences in the hospital than by deceased organ donation decision-making. The ethical principle of do no harm is the basis for health care professionals’ desire to ensure the family of the deceased consents to donation before allowing it to proceed (ANZICS, 2013; Dominguez-Gil et al., 2010; Fabre et al., 2010; NHMRC, 2007).

Studies have found that some health care professionals hold negative, ambivalent or cautious personal views about deceased organ donation, which include fears by some that the donor is not deceased before organ recovery. Other health care professionals suffer feelings of disgust regarding the operative procedure (Regehr, Kjerulf, Popova & Baker, 2004; Sanner,
Further, studies reveal some nurses and doctors who understand the pathology and evidence of brain death still have difficulty in believing brain death is death when justifying their ongoing care of the deceased body while circulation is maintained, which some perceive differently to their care for a body without circulation (Pearson, Robertson-Malt, Walsh & Fitzgerald, 2001; Sadala, Lorencon, Cercal & Schelp, 2006; White, 2003), and some experience moral distress related to the requirement to request DCD (Mobley, Rady, Verheijde, Patel & Larson, 2007). Variation between physicians in their decisions related to treatment at end of life, and resource limitations such as a lack of available ICU beds can contribute to pressure on a physician to withdraw treatment from a patient who potentially may become an organ donor, or decline to accept the patient into the ICU, which suggests the idea of ‘the roster lottery’ for end of life organ donation decisions (Wilkinson & Truog, 2013). Ethical guidance to health care professionals and particularly to physicians facing these dilemmas argues that ‘the appropriate response to moral uncertainty is to be guided by the wishes and values of the patient, not those of the physician’ (Wilkinson & Truog, 2013, p. 1130).

1.1.8 Contexts of unexpected end of life family decision-making

As previously mentioned, the donation decision is generally set within the context of a sudden catastrophic event, which in Australia, could be in a capital city, regional or remote rural location. This situation may require the critically ill patient to be transferred by road or aircraft over hundreds of kilometres for initial assessment, treatment and stabilisation, and admission to the critical care environments of emergency or intensive care. The circumstances that bring the families to the hospital are most frequently perceived as devastating by a family who may have witnessed the events, and then sought help and travelled long distances to be at the hospital.
Critical care environments are recognised as stressful not only for the patient, but also their families and treating staff (Pattison, Carr, Turnock & Dolan, 2013; Randell-Curtis & Puntillo, 2007; Stayt, 2007), and involve the use of complex, and what many perceive as frightening technology, which can potentially create physical, psychological and communication barriers between the patient, family and staff (Azoulay et al., 2000). Although families of critically ill and dying patients are known to need compassion from, and trust in care providers (Brooten et al., 2013) plus hope, information and proximity to their loved one, they do not always have these needs met (Verhaeghe, Defloor, Van Zuuren, Duijnste & Grypdonck, 2005). Furthermore, family inability to understand the health care team’s use of language and professional terminology has the potential to heighten family distress as they try to make sense of their grief and traumatic circumstances (Randell-Curtis & Vincent, 2010).

The context of end of life care in critical care environments is intrinsic to the donation decision. At present there is an emerging realisation that end of life care practices in acute and critical care environments may frequently not meet the needs of the dying and their families (Bloomer, Tiruvoipati, Tsiripillis & Botha, 2010; Hardy, Haberecht, Maresco-Pennisi & Yates, 2007). There is an emergence of the use of palliative care techniques in critical care environments to improve the quality of end of life care (Gay, Weiss & Nelson, 2012) with evidence suggesting the need for more research in this area (Bloomer, Morphet, O’Connor, Lee & Griffiths, 2013; Coombs, Addington-Hall & Long-Sutehall, 2012; Randell-Curtis & Vincent, 2010). Despite policy and organisational efforts to address these challenges it is known that the rights of patients at death are often poorly addressed or worse still, neglected (Neuberger et al., 2013). Dying in Australia’s acute care environments is currently under review (Australian Health
and Safety Commission, 2014) and efforts to address the needs of dying patients and their families are relevant to this study. Family presence at resuscitation (Fulbrook et al., 2007), advance care directives, registered donation wishes, and cultural and spiritual diversity add complexity to ideas of holistic end of life care. Further, the changing skill mix in critical care environments requires health managers to balance resource limitations (Ranse, Yates & Coyer, 2012) to best manage the needs of patients. This complexity is made more difficult by Australia’s geographic challenges to health care delivery caused by the ‘tyranny of distance’ (Blainey, 1966), which further contributes to the contextual milieu.

1.1.9 Bereavement implications for a family’s deceased organ donation decisions

There are bereavement implications for families who are asked to make a donation decision (Kesselring, Kainz, & Kiss, 2007; La Spina et al., 1993), with the possibility of harming the family if the grief is complicated by the experience of decision-making (Anderson, Arnold, Angus & Bryce, 2008; Holtkamp, 2002; Lichtenthal, Cruess & Prigerson, 2004). The idea of honouring a loved one’s wishes (Fulton, Fulton & Simmons, 2002), meeting the recipients (La Spina et al., 1993), reciprocity (Vernale & Pickard, 1990) and the possibility that the donation may be viewed as a sacrifice (Sque, et al., 2007) are important elements that may contribute to the bereaved experience of deceased organ donation decisions.

A multitude of factors are associated with deceased organ donation decision-making, and how these factors come together in the final decision remain unclear, but they appear to centre on the family experience of care at the end of their loved one’s life (Walker, et al., 2013). Contemporary ideas that involve end of life care in acute care environments include the
suggestion that it is possible to have a *good death* (Beckstrand, Callister & Kirchhoff, 2006) or a peaceful death (Hilton, Jones & Bellomo, 2013) in a critical care environment. The ideas about a good death in the critical care environment have for the most part been drawn from palliative care practices where the concept of the human right to a peaceful death has been proffered (Kirk, 2011). Cartwright (2004) proposed that ‘human beings, then, have the power of choice, and their exercise of that power will be much influenced by their having, or not having hope for a better future’ (p. 169). It is possible that the choices families’ make when they are forced to make an organ donation decision are balanced with their needs for survival and the needs of their family into the future. This study seeks to explore these complex areas.

**1.2 Purpose and aims of the study**

The purpose of this study is to identify the major factors that influence a family to agree or decline deceased organ donation during the process of decision-making. The aims of the study are three-fold: to identify the key stages and the major influencers’ in the decision-making process; to determine if hope, deep hope and trust play a role in the decision, and to explore families’ perceptions of their decision-making experience.

**1.3 Significance of the study**

This study will provide a significant contribution to the literature on both a practical and theoretical level. Firstly, this study will lead to a greater understanding of grieving families’ deceased organ donation experience of decision-making, and will contribute new knowledge about enablers and barriers to donation.
Second, this study will contribute to understandings of why high levels of community support for organ donation expressed in public surveys and organ donation registers do not translate to consent for organ donation at death.

Third, the findings from this study will provide a significant contribution to a gap in the literature regarding family deceased organ donation decision-making in Australia. An extensive search of published and grey research literature into bereaved families’ deceased organ donation decision-making experiences in Australia has revealed only two published interview studies of donor families (Pearson et al., 1998; Thomas et al., 2009), two published survey studies comprising one of donor families (Douglass & Daly, 1995) and one of donor and non-donor families (Pearson, Bazeley, Spencer-Plane, Chapman & Robertson, 1995), plus five unpublished quality assurance survey studies of donor families (White, 2008) which will be discussed in Chapter 2.

Fourth, this study will contribute to a deeper understanding of the decision-making contexts of DCD and DBD for bereaved families. The implications for family deceased organ donation decision-making in circumstances where the DCD process requires the withdrawal of life sustaining technology is poorly understood. This study will also explore donation decisions in the context of a medical decision to enable organ donation by maintaining organ-sustaining interventions to enable the determination of brain death and consideration of organ donation and the resultant decision-making implications for the bereaved family of the process of ‘beating heart organ’ donation’.
Fifth, this study will provide an important contribution at a regulatory and governance level because it will capture the experience of families who have made deceased organ donation decisions within the context of an evolving period of organisational, regulatory and policy change designed to increase organ donation in Australia. The period of this study includes the re-introduction of Maastricht Category III DCD processes into Australian critical care environments to increase the possibility of deceased organ donation (ANZOD, 2014).

The overall findings of this study will contribute to knowledge of how clinical guidelines, ethical frameworks, policies and legislation regulating deceased organ donation are interpreted and practiced, as well as their significance and relevance at the point of care for dying/deceased patients and their families, which will lead to recommendations. Importantly, this study will present and test an eclectic theoretical framework based on hope, deep hope and trust to explain the deceased decision-making process and contribute to building on the theory and knowledge of earlier studies.

1.4 Methodology and theoretical framework

Qualitative research techniques allow meaning to be revealed, and understandings and new knowledge to be developed from complex and individually distinctive situations (Denzin & Lincoln, 2005). A qualitative constructionist paradigm (Denzin & Lincoln, 2005) provides an appropriate framework to build an understanding of the challenging phenomenon of family deceased organ donation decision-making. Constructivism recognises that in life there are multiple realities that can be seen from differing perspectives depending on the position of the researched and the researcher (Denzin & Lincoln, 2005). When using a constructivist approach,
it is possible to acknowledge the differing ‘realities’ experienced by the participants as constructed and co-constructed as relative interpretations of realities (Denzin & Lincoln, 2005, p. 193). A qualitative research constructivist paradigm provides a philosophically robust framework to ‘reconstruct’ an understanding of the individual and family experience of making an organ donation decision, and the influencing factors that may have contributed to the family decision to agree or decline donation.

Case study research supports the examination of ‘how’ and ‘why’ questions where meaning may be obscured by the complex nature of phenomena under investigation, and where it is desirable to explore, interpret and construct the meaning (Yin, 2009). The exploratory nature of this research, and the sensitivity and complexity involved for individuals and their families when making deceased organ donation decisions requires a research design that will enable the complex contextual elements of the decisions to be described, and any factors that have hitherto not been considered to be included. Importantly, the study design must as far as possible protect the participants from potential harm caused by participation in the research. These requirements suggest that a case study approach would be an effective research design for this study to capture a range of experiences and views of deceased organ donation decision-making.

This study will therefore utilise an exploratory case study approach (Yin, 2009), a research design seen to fit within the constructivist framework. Such a design will support the analysis of family deceased organ donation decisions across different contexts of death and organ donation, thus supporting analysis of both within the case. This exploratory study does not seek to make generalisations, but instead to describe credible accounts, insights and
understandings from rich and authentic narratives of the decision-makers. Each participants experience of decision-making will be examined individually which will provide multiple perspectives of the case, which in this study is defined as the family decision-making process of deceased organ donation. Denzin and Lincoln (2005) argue that exploratory case study design contributes to the development of substantive theory that this study seeks to achieve through testing an eclectic theoretical framework.

The credibility of the study depends on the capture of authentic and trustworthy interview evidence from people who are best placed to understand and describe the experience; that is, volunteer bereaved families who are deceased organ donation decision-makers. Ethical and legal complexity surrounds the topic of this study and the potential participants and has been a barrier to previous research (Kiss et al., 2007). Following institutional ethics approval, recruitment will be conducted utilising qualitative purposive and snowball strategies. A researcher’s journal and field notes will also be kept to support researcher reflexivity and to aid analysis.

An eclectic theoretical framework employing the Precaution Adoption Process Model of decision-making (Weinstein, 1988) will be used to guide the study and to examine the role of hope, deep hope and trust, in family deceased organ donation decisions. This preventative health decision-making model is used to explain complex behaviours within dynamic and temporal contexts. The complex decision-making context of this study challenged me to consider if a more nuanced approach using this model would help to explain bereaved family decisions. Therefore, for the purposes of this study the model has been modified to include the constructs of hope.
(Snyder, 2002), deep hope (Coulehan, 2011) and trust (Job, 2007). The theoretical framework will be described in Chapter 2 and the methodology will be detailed in Chapter 3.

1.5 Limitations and major assumptions

This is a small exploratory case study with a small sample size. The findings cannot be generalised, but the participants’ views and experiences will reveal the complexity of the decision-making process encountered by bereaved families who made organ donation decisions. Their rich, meaningful contributions will provide insight into enablers and barriers to organ donation, which may resonate for other individuals and families who have also made deceased organ donation decisions, and for health care professionals involved in the practices of end of life care and deceased organ donation.

One major assumption has been brought to this study. A phrase used in my clinical practice of organ donation coordination has been ‘organ donors save lives, if you let them’. This statement is based on my clinical experience, and supported in the literature (Woolcott, 2012; Irving, Tong, Jan, Cass, Chadban, Allen, Craig, Wong et al., 2012) which suggests most people would like to help others following their death by donating their organs. I argue that this is a rational idea based on the supposition that most people in the Australian context are generous when they connect with someone in need. In the context of organ donation, statements such as ‘I’ll be dead, I won’t need them anymore’ are commonplace when people are asked if they are willing to donate. My experience suggests that the organ donation barriers are at a relational and organisational level within institutions. However, there has been insufficient research in this area to confirm this view.
1.5.1 Researcher position

I have practiced as a registered nurse and midwife in a wide range of critical care settings for over 30 years. My commitment to organ donation is related to insights gained while providing nursing care to patients who suffered and died from organ failure as a result of conditions that were treatable by organ transplantation. I also witnessed the courage and generosity of those who made donation decisions in four contexts of decision-making: those who had their offers of donation declined; those that agreed to organ donation; those who declined; and families that expressed guilt, believing they failed to honour their loved one’s wishes to donate because the question was not raised at death. My experience has taught me that organ donation can alleviate the human suffering both of those in need of transplant and their families. Organ donation can contribute to hope for those who are grieving; however, this benefit can only be conferred when the individual decision-makers’ needs are met. Nonetheless, grieving families’ hopes should not be traded for illusions of false hope. My involvement and conduct of this study requires me to be open and responsive to participants’ views and experiences. However, I must also balance and protect the needs of the participants and my own wellbeing in the context of deeply emotional experiences and ideas that are intrinsic to the study and its integrity.

1.6 Organisation of the thesis

This thesis is presented in five chapters commencing with Chapter 1, where I have introduced the study, its background and significance. In Chapter 2, I present a critical review of the literature that underpins this study, plus the theoretical framework. The chapter is divided into three sections. In Section 1, I present a historical overview of conceptions of death and the
development of deceased organ donation for transplantation practices, and their ethical and legal implications. In Section 2, I review the research literature, specifically examining the factors that contribute to family deceased organ donation decisions, and the needs of families that make those decisions. In Section 3, the theoretical framework utilised in this study will be presented and discussed.

Chapter 3 provides a description of the methodology utilised in this study. It describes how the research methodology will address the purpose and aims of the study. The philosophical underpinnings of the study are described, followed by the ethical considerations including participant selection, recruitment and reciprocity. The justification for the research design and its implementation and analysis are presented. A description of the methods used to maintain the trustworthiness and credibility of the empirical materials and analysis are provided. The positioning of the researcher and the applicability of the findings are described. Finally, the limitations of the study’s design and methodology are identified and discussed.

In Chapter 4 I first present a justification of the data analysis technique utilised in examining and interpreting the qualitative exploratory case study data. This is followed by a presentation of the demographic characteristics of the participants and the context of their decisions. The findings from the family members’ in-depth unstructured interviews describing their deceased organ donation decision-making experiences are then presented.

Chapter 5 presents the major conclusions and discussion drawn from the study findings. The conclusions are discussed within the context of the modified theoretical framework plus
previous research findings. A new 4 Point Precaution Adoption Process Model is proposed, which could be used as the theoretical basis to guide further studies on the deceased decision-making process of organ donation. This is followed by a discussion surrounding the implications for policy and practice, and recommendations for further research.

1.7 Conclusion

This chapter forms the foundation for this thesis by providing the reader with a background to the study and its significance. The context of deceased organ donation decision-making has been introduced along with the researcher’s position in the study. The methodology utilised in this study has been discussed, as have the ethical implications involved in undertaking research in this field of study. The significance and the implications of the study have also been discussed. The structure of the thesis has been explained and each chapter has been framed to aid clarity for the reader when conceptualising the content. In Chapter 2, I present a critical review of the literature that underpins this study plus the theoretical framework.
Chapter 2: Literature review and theoretical framework

2 Introduction

The range of literature relating to deceased organ donation is vast and sometimes poorly defined. Therefore, for clarity, the literature will be presented in three sections. Section One will present an historical overview of conceptions of death and the development of deceased organ donation for transplantation practices, and its ethical, legal and practice implications. Section Two will comprise a focused review of the research literature, specifically examining the factors that contribute to family decisions regarding deceased organ donation, and the needs of families who make those decisions. This section will include a description and analysis of the key studies that have contributed to a theoretical understanding of deceased organ donation decision-making. The literature in sections one and two will be presented chronologically to guide an understanding of the legal, ethical and practical contextual basis of the studies and the emergence of new ideas. In Section Three, the theoretical framework that will guide this study will be presented and discussed. The literature that underpins this study has been used in guiding the philosophical development, purpose and aims of the study. It has informed the theoretical approach to the study and has contributed to the development of the eclectic theoretical framework. The literature has been intrinsic in informing the ‘logic linking the data’ (Yin, 2009) for the collection of the empirical materials.

In summary, the literature review provides meaning and context to support the purpose of this study, which is to identify the major factors that influence a family to agree or decline deceased organ donation during the decision-making process. The aims of the study are three-fold: to identify the key stages and major influencers’ in the decision-making process; to
determine if hope, deep hope and trust play a role in their decision, and to explore families’ perceptions of their decision-making experience.

2.1 Literature sources

The literature used to inform this study was sourced from a range of databases and the Internet, including, but not limited to, SCOPUS, CINHAL, PubMed, MEDLINE and Cochrane. Search terms such as ‘organ donation’, ‘organ procurement’, ‘consent’, ‘refusal’, ‘family’ and related terms were used. The initial searches utilised broad time frames from 1960 onwards. Articles were reviewed if they were shown to contribute to an understanding of the context and practice of deceased organ donation. Government reports, seminal articles, primary and secondary sources and key citations known to the author were also reviewed, as were sources of contemporary community views such as social media and public domain information.

The selection of literature was refined to include literature pertinent to both international and Australasian contexts of organ donation decision-making. Seminal research and influential and frequently cited research articles regarding consent to deceased organ donation were included and the literature was accessed both electronically and manually. Reference lists were cross checked for pertinent literature that may have been missed.

2.2 Section One: Historical overview of death and organ donation from a global perspective

It is difficult to understand the contemporary practice of deceased organ donation and the context of the family decision to donate their relative’s organs without first examining the history
and meanings attributed to death, care of the dead and the use of deceased persons’ bodies and body parts. Death is integral to the practice of deceased organ donation; its consequences are fundamental in the organ donation request, and its meanings may engulf the donation decision. In this section I provide an overview of the major events and issues that have contributed to contemporary understandings of death and organ donation for transplantation practices; however, it is not within the scope of this thesis to provide a detailed analysis and description of these events and philosophies due to the extensive range of literature that has been presented on this topic. Further, it is not within the scope of this thesis to explore the literature on end of life care in critical care environments, which is a significant contextual element of deceased organ donation decision-making.

The ‘dead donor rule’ is implicit in deceased organ donation practices and underpins the assurances given to society and families of dying patients that the donor is dead before donating their organs (Kerridge, Saul, Lowe, McPhee, & Williams, 2002). However, according to Souter and Van Norman (2010), trust plays an essential role because ‘death is more than a mere biological occurrence. It has important legal, medical and social ramifications that make it imperative that those who are responsible for the determination of death be accurate and above suspicion’ (p. S502). The mystique of death generates a potent mix of emotions for families that are required to negotiate the circumstances around making organ donation decisions. The experience is further complicated if there is any uncertainty or distrust regarding the diagnosis of the death or question surrounding the time of death. It is significant that a definition of the exact time of death remains elusive, and that the skills, knowledge and signs that enable a doctor to
determine death with confidence and declare it to be irrefutable, continue to generate controversy (Kerridge et al., 2002; Powner & Ackerman, 1996; Souter & Van Norman, 2010).

Until recently, the presence of death was more likely to be determined by a priest rather than a doctor (Powner & Ackerman, 1996; Souter & Van Norman, 2010). Traditionally, the final illness leading to death most frequently occurred in the home of the dying individual, where relatives kept vigil until the person’s last breath, which signified the transition to death and the release of the soul (Shewmon, 2004). The declaration of death carries great social significance as ‘it allows survivors to progress from a state of caring to that of mourning, and one of expectation to one of conclusion’ (Souter & Van Norman, 2010, p. S502). This transition also exposes intrinsic embodied meanings held by individuals as they struggle with their hopes, fears and beliefs about existence, death and immortality (Coulehan, 2011; Haddow, 2005).

In a review of organ donation end of life ethical controversies, Souter and Van Norman (2010) provide insight into the complex philosophies and conceptions of death held by various religious and cultural traditions. They emphasise that clarity about the moment of death and its meaning remain contentious because efforts to achieve consensus on a definition of death and the moment of death are a recent advance, and argue that this lack of clarity has implications for the development of trust in those determining death and those that entrust their loved ones’ bodies to their care. Prior to this, death was only recognised when signs of ‘absence of breath and heartbeat were considered harbingers of death, and incineration, decapitation and purification indicators of its actual presence’ (Souter & Van Norman, 2010, p. S502). These ambiguities are
pertinent to the current study where death is declared using either heart beating or non heart beating criteria prior to organ donation.

2.2.1 Scientific understandings of death

The earliest understandings of the biology of death were documented in the 17th century by William Harvey (ANZICS, 2010). Harvey (1628) undertook the first anatomical description of the function of the heart and circulatory system and concluded ‘the heart, consequently is the beginning of life; the sun of the microcosm [and] … is the foundation of life, the source of all action’ (Chapter VIII), with evidence of death revealed ‘after death, when the heart has ceased to beat’ (Chapter IX, para. 11).

Scientific evidence of cerebral dysfunction leading to physiological decapitation and death developed with the work of Harvey Cushing in the late 19th century when he ‘observed that patients with cerebral pathology would die from respiratory arrest and subsequent circulatory collapse’ (Gardiner et al., 2012, p. i15). The implications of this altered sequence of physiologic failure heralding death became significant when mechanical ventilation was successfully used to prevent respiratory arrest (Widjicks, 2001) throughout the polio epidemics of the 1950s (Smith, 2012). This intervention created distress and ethical and legal complexity for families and staff when it was found that some mechanically ventilated patients remained in a persistent unresponsive coma showing no signs of cerebral function until cardiac arrest conclusively signalled death (Smith, 2012).
In 1959, French neurologists Pierre Mollaret and Maurice Goulon conducted a seminal study that examined the outcomes for 23 patients that had suffered severe brain injury and exhibited signs of unresponsive coma. They concluded that a new condition should be defined: ‘coma dépassé (a state beyond coma)’ (Pallis, 1984, p.105). This was described as a condition in which the patients had suffered ‘the disintegration of not only all relational responses between the individual and the outside world, but also of basic internal homeostatic mechanisms’ (p. 105). The consequences of these findings were described as ‘both a revelation (of the capacities of modern resuscitation and intensive care units) and a ransom (because of what the maintenance of patients in this state imposed on others)’ (p. 105).

In 1963, Guy Alexandre, a Belgian surgeon, presented seven cases involving patients that were described at a London conference as brain dead (Souter & Van Norman, 2010, p. S503). Controversially, among these patients was the first patient to become a ‘beating heart’ donor (Gardiner et al., 2012). Souter and Norman (2010) describe the ethical concerns raised by these and similar cases where brain death remained undefined and where ethical dissonance was compounded by the potential for conflict of interest in cases where the treating physician caring for the apparently brain dead patient would approach their family for consent to donate organs into another patient also in their care (p. S503). Thomas Starzl’s success in 1963 in conducting the first liver transplant on an 18-month-old child who died some months later is indicative of the kind of case that attracted scrutiny (Devita, Snyder & Grenvik, 1993). Doctors faced with the conundrum of continuing to treat patients displaying signs of unresponsive coma were led to make diagnoses and prognosticate on brain death with ‘imprecise and variable methodologies, creating fear of legal vulnerability’ (Souter & Van Norman, 2010, p. S503).
2.2.2 Consequences of heart transplantation

The effect of the first heart transplant, by Christiaan Barnard in South Africa in 1967, was to transform the public understanding of the benefits of transplantation (DeVita et al., 1993). It focused significant attention towards the skill of the surgeon, the medical team and recipient survival; however, the social and clinical context of the donor, their death and their family’s experience is unknown. In their review of deceased organ donation practices, DeVita et al. (1993) describe their surprise at the apparent disinterest displayed in the donor and ‘whether the donor was, or should be, dead … reversibility was not much considered’ (p. 114). Ethical difficulties for those involved in the South African case of organ donation after brain death included the very wide scope of interpretation of death, with Barnard claiming that it was acceptable to declare brain death because ‘legal authorities had left the definition of death imprecise, and that if a doctor so deemed, death of the brain was legally acceptable as evidence of death’ (1987, p. xix).

By 1968, concern regarding these fundamental ethical issues led ethicist and anaesthesiologist Henry Beecher to instigate the formation of an Ad Hoc Committee of the Harvard Medical School, comprising neurologists, theologians, neurosurgeons, physicians and others (Souter & Van Norman, 2010) to ‘define irreversible coma as a new criterion for death’ (Beecher et al., 1968, p. 84). The ethical basis of the ‘dead donor rule’ that ‘living patients should not be killed for or by organ procurement, but that vital organs can be taken from dead patients’ (Souter & Van Norman, 2010, p. S504) was made explicit when the committee provided recommendations to guide doctors to ‘identify how and why a patient should be pronounced dead’ (DeVita et al., 1993, p. 121). The purpose of the recommendations was to ‘(1)
decrease the burden on family and society that continued therapy would produce; and (2) update obsolete (i.e. cardiac) criteria for death that led to controversy in obtaining organs for transplantation’ (DeVita et al., 1993, p. 121). The committee’s findings provided guidance that without a change in the law, under specific conditions as agreed by physicians, the physician should have the authority to determine death using the conditions of unreceptivity, unresponsivity, lack of movements or breathing, absence of reflexes and a flat electroencephalogram (Beecher et al., 1968). The committee’s judgment that doctors should have the authority to determine the presence of death was supported legally and by religious groups, with Pope Pius XII quoted as saying ‘it is not within the competence of the church to determine this [time of death]’ (Beecher et al., 1968, p. 340).

The year 1968 was declared the ‘year of the transplant’ and it was also the year the first law guiding organ donation following death was introduced in the US (DeVita et al., 1993). According to Van Norman (1999), this law, known as the *Uniform Anatomical Gift Act* was ‘drafted in a climate of public concern about the potential illicit removal of cadaveric organs for transplant’ (p. 278). The legislation afforded US citizens aged over 18 years, and deemed competent, the ability to designate themselves as donors using donor cards; and authority to the next of kin when making deceased organ donation decisions (Van Norman, 1999, p. 278). This heralded similar legislative efforts around the globe.

The *Declaration of Sydney* was announced in the same year (1968) at the 22nd World Medical Congress held in Sydney Australia, and presented a philosophical framework for the diagnosis of death (Souter & Van Norman, 2010), and importantly ‘differentiated the meaning of
death at the cellular and tissue levels from the death of the person’ (Gardiner et al., 2012, p. i15).

According to these criteria, the diagnosis of death was seen as inevitable once a point of irreversibility was reached in the deterioration of cellular function (Souter & Van Norman, 2010). Importantly, the Declaration of Sydney also emphasised that the diagnosis of death was the doctor’s responsibility and should be performed without error (Gardiner et al., 2012).

2.2.3 Proof of death

Tangible evidence that the Harvard criteria were effective in confirming death of the brain was provided by seminal research entitled the National Collaborative Study for the Determination of Cerebral Death (Souter & Van Norman, 2010). The study sample consisted of 503 comatose and apnoeic patients receiving cardio–respiratory support. Of the 503 patients, 102 were assessed as meeting the Harvard criteria for brain death and were maintained on ventilator support until cardiac arrest, with their subsequent autopsies revealing ‘cerebral necrosis consistent with cessation of cerebral perfusion’ (Souter & Van Norman, 2010, p. S504). A critical appraisal of the criteria used in that study supported its effectiveness, adding that cerebral blood flow studies should be used to confirm an absence of circulation to the brain in cases where clinical testing is compromised (Walker, Bickford, Aung et al., 1977).

Until the 1977 Australian Law Reform Commission recommendations presaged the introduction of transplantation legislation, Australians donated their organs following the medical diagnosis of death using undefined cardio–respiratory criteria. The new legislation was based on a statutory definition of death described as ‘a) irreversible cessation of all function of the brain of the person; or b) irreversible cessation of circulation of blood in the body of the
person’ (Section 11, para. 136). Further, the commission advised, ‘as a reflection and confirmation of the Australian community’s general confidence in the medical profession’ (Section 11, para. 137) the medical profession should be responsible for the requirements for diagnosing death (Australian Law Reform Commission, 1977). These principles subsequently underpinned organ donation and transplantation legislation in all Australian states and territories (ANZICS, 2013). Following these changes, organ donation after brain death became standard clinical practice based on findings of improved outcomes for patients that received transplants of organs from ‘heart beating’ brain dead donors, compared with organs from ‘non heart beating’ donation from donors following circulatory death (Tait, 2012).

The 1981 (US) President’s Commission Report on the Medical, Legal and Ethical Issues in the Determination of Death discussed the intellectual dissonance present when ‘a dead person’s heart can beat in the chest of a living person whose own heart has not merely stopped but has been removed from his or her body’ (p. 16). The recommendations from this report sought to further elucidate the definition of death (ANZICS, 2013) and informed the 1981 US Uniform Determination of Death Act, which stated, ‘An individual who has sustained either (1) irreversible cessation of the circulation and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead’ (Souter & Norman, 2010, p. S504). However, Bernat, Culver and Gert (1981) argued that this definition did not alleviate confusion about brain death, proposing the only criterion for death should be the ‘irreversible cessation of whole brain functioning’ (p. 394). They were also concerned by the failure to explicitly specify the moment of death, proposing that death is ‘the event that separates the process of dying from the processes of disintegration’ (Bernat et al., 1981, p. 389). Further,
Youngner and Arnold (2001) argued that using the criterion of ‘irreversibility’ was flawed because ‘nowhere is irreversibility defined’ (p. 531).

International inconsistency in the methods used to determine death and to define death continues to contribute to the confusion held by health care professionals in providing care to dying patients and when discussing organ donation with family members. This confusion is heightened when medical and nursing staff travel and practice in countries that have different clinical and legal interpretations of what constitutes death. In 1996, the UK adopted the diagnosis of brain stem death as the determinate for death and organ donation (ANZICS, 2013). Pallis (1984), the British neurologist that drove the debate to accept brain stem death as brain death (Youngner & Arnold, 2001), emphasised the ‘failure to define death’ as the main cause of ‘inconclusive discussions about brain death’ (p. 101), contending that bedside clinical testing techniques were valid determinates of brain stem death. Pallis (1984) argued that ethical controversies linked to brain death are historical and have been caused by confusion at a clinical and conceptual level, and exacerbated by the use of inappropriate terminology, specifically citing ‘allowing to die’ (p.103) as an illustrative example.

Examples of this misunderstanding are evident in the findings of Siminoff, Burant and Youngner (2004), who conducted a survey study of 1,351 Ohio residents. High levels of public confusion were revealed when respondents were asked to clarify the circumstances under which organ donation is possible from scenarios describing brain death, coma and persistent vegetative states. Only 33.7% accepted that ‘someone who was brain dead was legally dead’ (p. 217), with many respondents apparently willing to donate the organs of patients that were not dead. This led
the authors to suggest that many in the community view ‘good as dead’ as sufficient for the purposes of organ donation (Siminoff et al., 2004). Veatch (2004) drew from these results to suggest that death should be redefined and the ‘dead donor rule’ abandoned. At the same time, Shewmon (2004) recommended the introduction of new terminology to more clearly describe the presence of death, believing this could help address societal confusion about death, the criteria for determining brain death and its relationship with organ donation practices.

Low donation rates, long waiting lists and evidence that improved techniques in organ retrieval were providing satisfactory outcomes from organs donated following signs of cardio–respiratory death (Muiesan et al., 2005) prompted a re-engagement with DCD practices as a means of increasing the number of organs available for transplantation. In Australia, guidance on how to determine cardio–respiratory death and a definition of death using circulatory criteria was provided to medical practitioners for the first time in 2010 (ANZICS, 2010); and 2008 in the UK (Gardiner et al., 2012). Dhanani, Hornby, Ward and Shemie (2011) conducted a review of the international guidelines and statements used for determining death following cardiac arrest, and identified a scarcity of peer-reviewed guidelines in the medical literature. They noted the lack of consensus regarding the length of time that should pass between witnessed cardiac arrest and the declaration of death, ranging from 2 to 10 minutes. They recommended that ‘clear consistent guidelines based on evidence were needed to fulfil medical, ethical, and legal obligation and to ensure public trust’ (Dhanani et al., 2011, p. 1).

Community expectations regarding the influence of time, and how long after a death is confirmed it is reasonable to allow surgery to remove organs, are poorly understood. Rogers, de
Lacey and Avery (2011) conducted a study examining community views about the acceptability of DCD processes in the context of the time required between the declaration of death, and organ recovery. Findings from four focus groups comprising 32 participants were used to contribute to a larger survey study of 2,824 participants from the South Australian community. The authors identified that 42.5% of participants accepted a time frame that was compatible with successful transplantation and found that some participants believed that in the time that elapses after physical evidence of death ‘the person or the soul was in limbo … [and not] considered to be truly or fully dead, or … actually dead, dead’ (Rogers et al., 2011, p. 584). It is therefore possible that when a family is asked to donate organs in circumstances of DCD using times as short as two minutes between the dying patients’ loss of cardiac output and the declaration of death, followed by a rapid transfer to the operating theatre, they might perceive the timing as indecent. Rogers and colleagues’ (2011) findings suggest that more than half the study participants would be reticent to agree to donation in these circumstances. This has significant implications for family consent to DCD.

Today, international practices, laws and criteria for the declaration of death remain inconsistent (Gardiner et al., 2012; Shemie et al., 2006; Wijdicks, 2006). In the US and Australia, brain death is diagnosed as the irreversible loss of all function of the brain and brain stem (ANZICS, 2013), whereas the UK only requires the confirmation of irreversible cessation of all function of the brain stem (Gardiner et al., 2012; Pallis, 1984). Spanish practices require more rigorous testing to determine brain death compared with the UK (Gardiner et al., 2012), and will not allow ventilator support to be removed from any patient until death is confirmed. Brain death is recognised in Jewish Law and is determined using instrumental and clinical testing (A.
Steinberg, personal communication, 22 October 2012). Rady, Verheidje and McGregor (2010) presented a study on the evolution of methods used to determine and define death since the 1967 practices used by transplant surgeons such as Starzl and Barnard. The authors argued that there has been erosion in the way death is defined and diagnosed in the US, and they believe that this has undermined the protection of patients’ best interests, as well as the credibility of the determination of death in circumstances of organ donation (Rady et al., 2010).

Gardiner et al. (2012) conducted an international literature review on the diagnosis of death, and specifically drew from the 2008 Consensus Statement of the Presidents’ Council on Bioethics in the US, citing ‘all criteria to diagnose human death rely upon the demonstration of the irreversible loss of the capacity to breathe, combined with the irreversible loss of the capacity for consciousness’ (p. i15). They proposed three methods to diagnose death as part of a unifying concept of death, which encompassed somatic criteria including obvious signs such as rigor mortis, decapitation and decomposition; cardio–respiratory arrest criteria; and confirmation of death using neurological criteria based on the Harvard criteria. The authors (from Australia, Canada and the UK) agreed that the criteria were ‘robust, specific and based on scientific principles’ (Gardiner et al., 2012, p. i14); however, the debate continues today.

2.2.4 Revising brain death criteria

Proponents for a revision of the criteria for brain death have continued to question the ethical and biological interpretations of whole-of-brain death and brain stem death. Suggestions have been made that organ donation from minimally conscious patients at the end of life and from patients in vegetative states or those with anencephaly should be considered (Gardiner et
al., 2012). Some authors suggest using the ‘higher brain formulation [which is] … death as the loss of what is essential to the person’ (Abram et al., 1981, p. 50); a view that is balanced against those ‘that believe locating human death to functions in the brain is reductionist and does not accord the body with sufficient dignity’ (Gardiner et al., 2012, p. i25). Philosophical and clinical debate has continued to challenge these conceptions of death and its determination, particularly as DCD has re-emerged as a method to address organ shortages (Dhanani et al., 2011).

A continuing dissonance exists in the public dialogue in Australia about the determination of brain death and organ donation, which may undermine community confidence in organ donation practices. The renowned ethicist Tonti Filipini (2008) is cited in the Australian press arguing that despite the benefit he would obtain from receiving a renal transplant, he continues to refuse to accept one from a deceased donor because of his distrust of the method of determining brain death in Australia. This view is supported by Tibballs (2008), an intensivist that argues that the Australian community’s ‘distrust of whole brain death as defined by brain stem criteria’ (p. 337) influences the number of families that decline organ donation, citing legal case history to support his argument. Tibballs (2008) posits that the clinical method of declaring brain death only confirms brain stem death and is insufficient to confirm whole brain death, which is required under Australian law, and proposes that brain perfusion scanning should be added to routine tests used to confirm the loss of whole-of-brain function.

The confusion and ambiguity that exists in understanding, diagnosing and communicating about death and organ donation has potentially significant ramifications. According to Souter and Van Norman (2010) ‘misdiagnosis has occurred and almost certainly
resulted in the unintentional killing of donors, some of whom may not have been otherwise at the end of life’ (p. S504). It is possible that these and similar findings may have negatively influenced the practice of health care professionals and their attitudes towards donation, especially as evidence exists that the cases were not unique (Van Norman, 1999). According to the literature, medical and nursing professionals often display ambiguous attitudes towards organ donation (Pearson, et al., 2001; Pearson & Zurynski, 1995), with operating theatre nurses known to refuse to designate themselves as organ donors, expressing fears that organ donation may contribute to the death of the patient (Regehr, Kjerulf, Popova & Baker, 2004).

Souter and Van Norman, (2010) describe the contemporary role of the physician in declaring death, as being imbued with a ‘mystique and power’ (p. S503) because of a special skill set that is not obvious or available to the community. They argue that the intrinsic trust implicit in this role is undermined if there is any perception that the physician has made an error or is untrustworthy, which could have significant implications for the grieving family. When the trauma of sudden and unexpected death is juxtaposed with a request for organ donation, the possibility for confusion and conflicts of interest become apparent (Souter & Van Norman, 2010), as will be explored further in the current study.

2.2.5 Primum non nocere

The Hippocratic Oath ‘Primum non nocere: Above all [or first] do no harm’ (Beauchamp & Childress, 2009, p. 149) has been used to direct medical behaviour since approximately 450–380 BCE (Boylan, 2005). Beauchamp and Childress (2009), in their treatise on the principles of biomedical ethics, argued that throughout history the guiding ethical principle of
nonmaleficence, which underpins this dictate, has often been poorly applied especially in areas of truthfulness, the use of research subjects and the distribution of health care resources. It is possible that examining this past may help reveal the roots of the ambiguous response displayed by the community to requests for organ donation, especially in the context of the trust relationship formed between the physician that is caring for the deceased at the time of the organ donation request and the family that decides.

Historian Ruth Richardson (2006), who was aware of historic parallels between a contemporary distrust of procurement and transplantation practices and practices involving the dead, conducted a longitudinal review of UK practices involving the dead from the 16th century until the present. The purpose of the study was to understand contemporary issues, including organ shortages, by examining past practices involving the dead body. The review is contextually relevant to this study because, although Australia’s cultural heritage is diverse, the British ancestry and historic cultural and institutional associations of many Australians is likely to influence behaviour in Australia. Further, legal and medical practices include the expectation that the physician responsible for treating the patient should also manage the organ donation request (ANZICS, 2013). Richardson (2006) found strong traditions in the UK of caring for the dying and dead in their homes, finding that families would care for the body, with female family members cleaning and dressing the deceased in preparation for viewing by mourners. Customs included touching or kissing the body and observances for the spirit to protect the living from being haunted, and it is possible these practices continue. The body was perceived to have a sentience and was carefully attended in the home for days after the death until the burial.
Communities had a literal belief in the biblical description of resurrection, hoping their buried dead would awaken, arise and they would be reunited (Richardson, 2006).

Anatomy has long been taught using dissection and Richardson (2006) described how, as more corpses were needed, the retributive law was reviewed to include public dissection as a death sentence punishment for murderers, to ensure ‘physical and spiritual obliteration’ (p. 154). Medical demand eventually exceeded the availability of corpses, and Richardson (2006) illustrated the scope of the problem using the example of William Harvey, who was famed for describing the circulation of the blood in 1628 after dissecting the bodies of his father and sister. Over time, with increasing pressure for a supply of ‘fresh’ corpses, medical schools procured illegal corpses from body snatchers (Richardson, 2006). Grave robbery became increasingly common and stolen bodies were quickly dismembered and sold; with distressing consequences not only for the population of the UK, but other countries including the US (Richardson, 2006).

According to Richardson (2006), the 1832 Anatomy Act was introduced in the UK to increase the supply of legal corpses and put an end to profligate grave robbery. The Act directed that bodies of those unable to pay for their funerals should be used for dissection, leaving open the charge ‘that the destitute were to be dissected in the name of scientific progress’ (p. 161). Richardson highlighted that the Act had an opt-out clause, ‘that the poor could choose not to be dissected by swearing to this fact in front of two witnesses. But the opt-out clause was unenforceable inside a Poor Law Workhouse, where the only witnesses were as powerless as the dead’ (p. 161). Despite the exploitation of the poor, a shortage of bodies for dissection continued until the Second World War when the dead were still taken from mental institution mortuaries.
for dissection (Richardson, 2006). The establishment of the National Health Service in 1948 brought about a substantial increase in voluntary donation motivated by altruism (Richardson & Hurwitz, 1995), and balance was attained between the number of bodies required for dissection and those donated (Richardson, 2006). Richardson concluded that a continuing belief in the sentience of the deceased and a fear of harming the dead may influence negative organ donation behaviours, coupled with a ‘profound repugnance towards physical interference or mutilation after death’ (2006, p. 163). Significantly, she also concluded that community trust in deceased donation practices had been undermined because many transplantation advances had been based upon practices such as ‘body snatching, medical murder and the indignity of dying in poverty’ (p. 163), arguing the findings were internationally relevant to the acceptance of deceased organ donation.

Allan Kellehear (2000) edited the first scholarly interdisciplinary work to examine death and dying in Australia. This was an important contribution to help professionals and others understand the experience of palliative care contexts of dying for people facing life limiting conditions. This work touched on suicide but did not explore the Australian context of dying and death in circumstances of traumatic or sudden unexpected death and did not examine the relationship of organ donation decision-making and death. There is a dearth of literature regarding death and family organ donation decision-making experiences in Australia.

2.2.6 An overview of transplantation practices

John Hunter, the 18th-century ‘father of scientific surgery’, conducted a range of experiments involving animal transplants including the successful relocation of a human tooth
into a cockerel’s comb (Richardson, 2006). In 1778, Hunter described experimental findings that ‘teeth after having been drawn and inserted into the sockets of another person, unite in the new socket, which is called transplanting’ (cited in Richardson, 2006, p.157). Unfortunately, Hunter’s efforts to transplant tissue between humans created ethical controversy when he used unscrupulous practices to replace the rotten teeth of wealthy patients with the freshly extracted newly erupted second teeth from children (Richardson, 2006, p. 158). Many impoverished children had all their teeth removed and transplanted into wealthy recipients before the transplanted teeth were rejected, revealing that the technique had failed (Richardson, 2006). These practices ceased when a young woman contracted syphilis and died following a tooth transplant (Richardson, 2006). It would be many years before the transmission of infection and the immune response would be understood, and Hunter refused to believe he had caused the damage. Richardson (2006) described this as Hunter’s blindness, which she defined as ‘the ability to focus so narrowly on recipient-benefit as to excise the humanity of the donor from contemplation’ (p. 159), an idea that continues to be relevant in contemporary discourse and practices involving organ donation. After this controversial period, progress in transplantation stagnated for another century.

Watson and Dark (2012) reviewed the history of organ transplantation commencing with the 19th-century success of Mathieu Jaboulay and Alexis Carrel, who developed the surgical techniques enabling circulation to transplanted organs. This effort was followed in 1906 by unsuccessful human transplants of animal organs and in 1936 by the efforts of Voronay, a Ukrainian surgeon that treated a patient dying from renal failure by performing the first human organ transplant six hours after the death of the kidney donor. The treatment in this case and five
others proved unsuccessful because clinicians were unaware of the damaging effects of warm ischaemia on organ function (Watson & Dark, 2012).

Successive decades saw developments in organ transplantation that included the perfection of surgical techniques and the identification of the role of the immune system. The work of Peter Medowar in understanding skin graft rejection during the Second World War revealed the importance of developing therapies that were able to mediate the immune response and enable successful transplantation (Watson & Dark, 2012). In 1960, Medowar and Sir Frank Macfarlane Burnet jointly received the Nobel Prize in Physiology or Medicine for their work in acquired immunological tolerance (Nobel Foundation, 2014). In 1954, a kidney was successfully transplanted from a young man to his identical twin brother by Joseph Murray and his team in Boston (Watson & Dark, 2012), providing proof that the immunological response played a role in the bodily rejection of a tissue graft. In 1990, Murray received the Nobel Prize in Physiology or Medicine in recognition of these achievements (Marshall & Morris, 2012).

DeVita, Snyder and Grenvik (1993) were concerned about the shortage of organs as the success of transplantation continued to grow and conducted a review of the lay, medical and ethics literature on cadaver donation, aiming to ‘trace the evolution of solid organ procurement and transplantation’ (p. 113–114). Their findings revealed key issues and events including ethical questions about the practices and outcomes of organ transplants, and that transplantation success rates from donated organs from deceased patients were approximately 50% less than those transplanted from live donors during the 1960s. It was noted that early enthusiasm for living donation declined when the risks to the live donor were revealed and concerns about unethical
practices such as coercion and organ sales became evident; thus transferring pressure to transplant teams to access donated kidneys from deceased donors (DeVita et al., 1993). The authors highlighted the complete lack of interest in the implications for the donor when they pointed to a 1964 medical textbook in which a chapter on the ethics of organ donation contains only two sentences about the donor, proclaiming that ethical implications for the donor were insignificant (DeVita et al., 1993, p. 119).

Strategies to address the burgeoning need for more organs were broadened to incorporate heart-beating donors ‘who died in the operating room because they could not survive the removal of cardio–pulmonary bypass after open heart procedures’ (DeVita et al., 1993, p. 117). The authors describe the practice, commencing in 1962, in which the surgeon knew the patient was certain to die and so the kidneys were surgically removed while the patient remained alive on bypass support in the operating theatre (DeVita et al., 1993). Other contentious cases included a 1964 Swedish case in which a family gave their consent, for unknown reasons for the removal of a kidney from a family member, which was transplanted into another patient. Two days later the donor patient was declared dead after cardiac arrest, which led to a public outcry that ‘may have contributed to Sweden being two decades behind other western countries in passing brain death legislation’ (DeVita et al., 1993, p. 118).

An editorial written in 1964 for the *Annals of Internal Medicine* by its editor J. Russell Elkinton revealed the author’s concerns about public perceptions of organ donation and transplantation, and the implications for public distrust if rigour in medical communication about these practices was not properly addressed. Elkinton (1964) argued the need for professional
accountability in the reporting of transplantation outcomes, expressing concern over his observations of poor ethical and legal analysis of transplantation practices and their ramifications. Elkinton (1964) reflected that transplantation therapies offer ‘great hope for many patients with organs diseased beyond any chance of healing or repair’ (p. 309) but argued that false hope is raised when imbalanced reporting leads to promotion of the success of the transplant, without giving equal reporting to the news of the subsequent death of the patient. Elkington (1964) proposed a role for shared accountability in setting trustworthy public expectations about organ transplantation, which he suggested should begin with the referring medical physician and extend across the ‘lay public relations man or science writer and the experimenting physicians and surgeons’ (p. 312).

Francis Daniels Moore (1988), professor in surgery at Harvard University and US chief surgeon argued in an essay that the ‘ancient dogma of first do no harm was window dressing for the necessary hurt that has accompanied much of medical practice over the centuries’ (p. 1061). The author suggested three ethical assumptions had been altered during the practice of organ transplantation, including the principle of first do no harm, followed by the ethic of therapeutic innovation and desperate remedies, and finally the concept of the ethic of limits of voluntarism (Moore, 1988, p. 1061). Moore’s argument focused on the questionable motivations of individuals within institutions that performed experimental surgery in cases where desperation was used as an argument to conduct untested procedures on dying patients. He cited examples of where the benefits of prestige, funding and publicity for the institution, rather than scientific evidence or the patient’s best interests may have motivated the surgeon to conduct the procedure, highlighted the complicated motivations involved in organ donation practices and identified
another avenue by which public trust may be undermined in the context of the false hopes of desperate patients and media interpretations of their plight (Moore, 1988).

The president of the Southern Surgical Association, Arnold Diethelm (1989), in a review of ethical problems relating to organ transplantation, concurred with Moore’s (1988) view that new transplantation procedures should have a scientific basis and be undertaken with expertise and institutional ethics approval. Diethelm (1989) expressed concern about the ethical implications of changing donation practices, including the organ trade between impoverished people in under-developed countries, and the use of organs from death row prisoners. He highlighted the ethical implications of modifications of practices used in the declaration of brain death and the introduction of laws to mandate organ donation requests from the families of brain dead donors as a method to increase donation rates. He suggested it is wrong to assume that families of deceased patients would understand the need for transplantation and accept brain death, proposing that ‘the lack of organ donation is not the result of selfish people but rather a lack of education about the subject, and especially involves those with different social, cultural and ethnic backgrounds’ (p. 514). He concluded that successes of immunosuppression therapies and the shortage of organs should make those responsible in pleading for additional donors take care that the ethical conscience at ‘play does not become a farce’ (p. 519). Dielthem’s argument remains relevant today and will be examined further in this study.

2.2.7 Australian Perspectives on Deceased Organ Donation

The first recorded deceased organ donation for transplantation in Australia took place in 1956 with the removal of a kidney from a ‘recently deceased cadaver donor’ in the morgue at the
Royal Melbourne Hospital (Marshall & Morris, 2012, p. 5). The kidney was transplanted into a young man where it was hoped it might function long enough to allow the patient’s own kidneys to regain function; however, the intervention was unsuccessful and the patient died (Marshall & Morris, 2012). The identity and motivations of families that provide consent for organ donation have long been hidden from public view for reasons of ethical protection (NHMRC, 2007; Pittman, 1985). Information about the families of this donor and others, and details about how they were approached for organ donation is not publicly available. Such details are likely recorded in the confidential medical notes of the recipient and possibly the deceased patient. The common practice during the first decade of organ donation was for the renal transplant surgeon or, less frequently, the intensive care specialist caring for the dying patient, to approach the family to seek their approval for the donation of their relative’s organs (Morton & Leonard, 1979). The family then and now was considered to be ‘everyone who might consider themselves next of kin, for example de-facto and legal wives’ (Morton & Leonard, 1979, p. 239), which fits with the definition of family used in the current study.

In 1985, concern about the paucity of care given to potential donor families in Australia was raised by Susan Pittman, a social worker involved in the heart transplant programme, who expressed her moral apprehension about the care received by potential donor families and the families of donors, in a discussion article published in the *Medical Journal of Australia*. Pittman (1985) emphasised that little was known about the donor family experience, and expressed concern regarding the effect of media attention for the recipient and the transplant team and poor acknowledgement of the donor family. She suggested that for the first time society was faced with complex donation issues without developing mechanisms for supporting the donor family.
Pittman proposed that the ‘grief is made more complex by the donation of the heart because a part of their dead relative’s body has been implanted, and is living in someone else’s body’ (p. 568). Pittman compared Australian donor family support with that available in the US, and concluded ‘the lack of recognition and acknowledgement certainly exacerbate the anguish of the family of the donor and many have asked why their story remains untold’ (p. 569).

Australian philosopher Peter Singer (1994), in an exposition on the ethical dilemmas affecting contemporary understandings of life and death, highlighted the moral dichotomies regarding understandings of death and organ donation practices. For example, he described how advances in intensive care skills enable brain dead pregnant women to be supported for months until their foetus is considered viable, and delivered. Singer described how the idea of utilising the body as a *vessel* was captured in community debate in two cases where brain dead women received technological support to maintain their body function for the purpose of growing an *embryo*. He suggested that ideas of a right to life appear to conflict with the ideas of a right to a dignified death in these circumstances, proposed that despite their appearance of life, once a patient is declared brain dead they lose all human rights, and argues that the rights of brain dead patients were lost when the 1968 Harvard Brain Death Committee Report enabled the determination of death for practical purposes. Singer suggests ‘the change in our conception of death that excluded these human beings from the moral community was among the first in a series of dramatic changes in our view of life and death’ and asks, ‘How did this happen?’ (p. 23). Ideas around human rights and donors’ rights to a peaceful death will also be examined further in the current study.
The reintroduction of controlled DCD processes has contributed to moral confusion for some medical and nursing staff that perceives a potential conflict of interest between the needs of the dying patient and those of the potential recipient. This dilemma presents when life-sustaining therapies are discontinued in anticipation of planned organ donation. The ‘doctrine of double effect’ (White, McDonald & Willmott, 2010, p. 492), seen when the benefit of administering analgesia and sedation is balanced against the risk of hastening death, further complicates the situation. This dichotomy becomes apparent in the provision of palliative care after life-sustaining therapies are ceased. Other controversial pre-mortem interventions (Tibballs, 2008) used only to improve transplantation outcomes and that provide no therapeutic benefit to the dying patient include the use of heparin to assist organ function. It is argued that this practice is tolerable because it contributes to the patients’ autonomous wish to help others (Richardson & Rogers, 2007). Tibballs (2008) contends there is ‘antimony’ (p. 351) between contemporary Australian DCD guidelines and the law, proposing that the national guidelines failed to receive legal scrutiny.

In conclusion, since the work of Harvey in 1628, almost 400 years elapsed before the criteria of circulatory death and the tests to determine it were defined. The impetus for this practice clarification arose because of the need to operate within minutes of circulatory standstill to recover still-functioning organs for transplantation. Nevertheless, philosophical and clinical debate continues to seek to determine the best methods of defining death, the accuracy of the time of death, and the quality and consistency of the clinical practices used to confirm it. Society has left the skills and responsibility of accurately determining the time and presence of death entirely with the medical profession, a trust that is implicit in the acceptance of deceased organ
donation procedures. It is possible that doctors involved in declaring death need to demonstrate greater transparency in their actions and communications with families when approaching end of life care and deceased organ donation processes, and take responsibility in making their actions explicit. The degree to which families experience open communications when approached about deceased organ donation will be explored in the current study.

Families that are asked to agree to donation, and the health professionals who advise them about death and organ donation processes, are at the interface of any confusion regarding when dead is dead. Anecdotal views held by some critical care nurses propose, ‘you’re dead when the doctor says you’re dead’. Ongoing ambiguity for families facing decisions for family members about the withdrawal of life-sustaining treatment and the declaration of death have significant implications for the development of hope, deep hope and trust for those making deceased organ donation decisions. These issues will be explored further in Section Three of this chapter.

2.3 Section Two: A focused review of the evidence-based organ donation literature

This section takes a focused approach to reviewing the literature pertaining to factors that contribute to family deceased organ donation decisions, and the needs of families that make those decisions. It includes a description and analysis of the key studies that have contributed to a theoretical understanding of deceased organ donation decision-making. The literature is viewed through the lenses of organ donation organisations, donation requesters and decision-makers.
Importantly, this review identified a significant gap in the literature regarding the experiences and views of family deceased organ donation decision-makers in Australia and globally. There is limited research exploring bereaved families experiences of organ donation decision-making in the contexts of DCD and DBD. Much of the literature and analysis of the decision-experience is drawn from small numbers of donor families who have agreed to participate in survey studies conducted by OPO’s, whilst the majority of families who agree or decline to donate are not represented in the studies or literature. Further, the Australian deceased organ donation decision-making context is poorly represented in the literature.

2.3.1 Factors that influence family decisions, through the lens of organ donation organisations

The need for organs has been the primary driver for research into factors that influence family decisions, and most studies have been conducted by US organisations responsible for facilitating and increasing deceased organ donation (Simpkin, Robertson, Barber & Young, 2009). As previously mentioned, the introduction of successful transplantation techniques meant the demand for organ transplants rapidly outpaced supply (Cass, et al., 2010; Hibbard, et al., 1992). When the general assumption that families would willingly donate their deceased relatives’ organs was challenged by family refusals, this was put down to irrational grief (Harris, 2003) and that grieving families are too distraught to make informed decisions (Wilkinson, 2011, p. 69). Calls for legislation to enable organs to be recovered without family agreement surfaced in countries where audits revealed significant numbers of families had declined organ donation requests (Chisholm, 1988).
Geoffrey Chisholm, director of the Nuffield Transplant Unit, in an editorial published in the *British Medical Journal* called for an end to the ‘softly softly approach to harvesting organs’ (Chisholm, 1988, p. 1419). He was concerned about a growing gap in the UK between available organs and recipient needs when discussing audit evidence of hospitals failing to approach families to donate their deceased relatives’ organs. Chisholm called for the UK to adopt a similar approach to the US, where laws mandating organ donation requests were tied to financial reimbursement for health organisations. He articulated his disquiet in not knowing why families declined organ donation requests, commenting that ‘the exact reasons for refusal are often not asked, but a common statement is that relatives feel that the patient has already been ‘through enough’ (p. 1419). Chisholm voiced his frustration at being unable to understand the meaning behind this statement, suggesting that the real reason families declined might never be known. Despite this challenge, little research has been conducted involving bereaved families to conclusively identify the factors that contributed to their refusals or to clarify the above statement.

Simpkin, Robertson, Barber and Young (2009) conducted a systematic review of the modifiable factors that influence relatives’ organ donation offers, and concluded that deceased organ donation decisions are contextually located within family perceptions of the relationships and care provided by hospital health professionals to their family member. Thus, previously held positive views towards donation may not be sufficient motivation for a family to agree to organ donation if the relationships and experiences in the hospital are not what the family expected, further highlighting the importance of researching decision-makers’ views. However, accessing bereaved decision-makers to invite their participation in studies may require overcoming
potentially complex organisational barriers. Batten and Prottas (1987) lamented that some organisations are averse to involving organ donation decision-makers in studies and may decline participation. Alternatively, some decision-makers may perceive a conflict of interest between health professionals and themselves, which may be a barrier to participation in some studies (Holtcamp, 2002).

Importantly, it is known that donor families are more willing to consent to participate in studies than are non-donor families (Batten & Prottas, 1987; Kiss et al., 2007). A number of reasons have been proposed for this imbalance, including the possibility that the grief related to the experience is too burdensome for a family to allow their participation (Holtkamp, 2002; Tymstra, et al., 1992), or that families who regret their decision may be unwilling to discuss it further (Burroughs et al., 1998). Therefore, in previous studies, researchers have identified that access to families that have been asked to donate their family member’s organs may be limited for ethical and organisational reasons (Sque, 2000), and some studies have utilised incentive payments to encourage participation (Exley, White & Hoot-Martin, 2002). This complex contextual milieu creates difficulty for researchers seeking to explore accounts from authentic and trustworthy sources.

Hospital death audits and retrospective chart reviews are a convenient research strategy used by organ procurement and transplant organisations to examine organ donation performance and the influence of modifiable factors within the hospital environment, in order to increase organ donation rates (Simpkin et al., 2009). Death audits were initially designed to identify the potential for deceased organ donation, and provided a significant contribution to the literature by
building understandings of the complex relational and organisational dynamics present in clinical environments where organ donation is possible. Death audits using chart review have allowed researchers to analyse patients’ demographic details, treatment and circumstances of death along with evidence of discussions between health professionals and family members.

One such study came about after statistics revealed Australian kidney organ donation rates were lower than those in the UK and US. This led the 1989 New South Wales (NSW) organ transplantation organising committee to undertake a prospective death audit to measure the potential for cadaveric organ retrieval in NSW, and to identify the reasons for potential donors not becoming donors (Hibbard et al., 1992). Funded by the NSW government and a pharmaceutical company, and with ethics approval, Hibbard et al. (1992) in 1989 conducted a 12-month prospective audit of all patient deaths in five NSW hospitals. Unlike previous published research, this study was designed to examine all hospital deaths, proposing that brain death may occur not only in ICUs but in emergency departments and other hospital locations. Definitions designed to classify and determine medically suitable potential organ donors, missed potential donors, the donor consent rate and reasons for potential donors not donating were developed and used as outcome measures. Of the 2,879 deceased whose deaths were reviewed, 73 were assessed as being medically suitable potential donors. Of these, 30 were missed, 19 became organ donors, 19 families declined organ donation, and five involved organ function failure. The most significant factor inhibiting organ donation was a physician’s decision to not provide support for organ function, which occurred in 26 cases, followed by family refusals (Hibbard et al., 1992). The problem of physicians using inconsistent practices and demonstrating
Morris, Slaton and Gibbs (1989) conducted a three-year retrospective death audit of a hospital in Tennessee to specifically assess the potential donor pool, the characteristics of donor vs. non-donor families, the role of physicians in the donor shortage and the effect of a regionalised trauma centre on donation rates. Within the period of the study the authors identified 61 ‘eligible donors’ from a total of 189 deaths. They divided the eligible donors into those where organ donation was approached (47 cases) or was not approached (14 cases); and those where families agreed (27 cases) or declined (20 cases) donation. Comprehensive demographic information about the potential donors was collated including donor card and insurance status. Fifty-seven % of families agreed to the request for organ donation; however, statistical analysis did not reveal specific factors that influenced their decision-making other than that ‘the non-donor group had a mean bad debt 2.6 times that of the donor group’ (p. 785). The authors reported that the donor group was significant because it was ‘the only group to show a profit for the hospital’ (p. 783). The study found the highest family refusals were noted when the death occurred 4–6 days following the injury, and concluded that the donor pool was smaller than hypothesised (Morris et al., 1989).

Interestingly, physicians had failed to ask for donation in 23% of cases, apparently on socioeconomic grounds, and noted family refusals were linked to lower socioeconomic factors (Morris et al., 1989). The study was limited by its small sample size and the specific characteristics of the centre and its location. However, the findings point to the importance of
considering socioeconomic factors in approaches to requesting organ donation and the experience of family decision-makers, and reveal that economic influences and funding models may influence health professionals’ behaviour towards requesting donation.

This idea finds relevance in Australia, where reimbursing hospitals for the cost of facilitating organ donation was suggested as a means to achieve increased hospital engagement in increasing organ donation rates (Oberender, 2011). However, the suggestion was immediately misinterpreted by the media, with some sources labelling it ‘cash for organs’ (Oberender, 2011, p. 639) and claiming that hospitals could benefit financially from organ donation by their patients. This example of media misrepresentation and the controversy it created has the potential to undermine community trust in organ donation, especially when organ donation is represented as an altruistic gift. Morris et al. (1989) also recommended that trauma centres attempt to increase organ donation rates via specific physician and public education, which remains pertinent today given the increasing realisation that requesting organ donation from family members in emergency departments may lead to an increase in rates of organ donation (Garside & Garside, 2010; Robey & Marcolini, 2013).

Bereaved families’ concerns that additional costs may be incurred when agreeing to organ donation were first identified in a US study by Fulton, Fulton and Simmons (1982) and also reported in subsequent studies (DeJong et al., 1998; Savaria, Rovelli & Schweize, 1990; Siminoff, Gordon, Hewlett & Arnold, 2001). Minority groups have been identified as more likely to refuse to donate (Brown et al., 2010) and societal disenfranchisement of the vulnerable and poor within the community possibly contributes to donation refusals. Siminoff and Mercer
(2001) reported that a funeral benefit was offered as a financial incentive to encourage families
to consent to donation in a trial conducted in the US state of Pennsylvania. Although the
outcomes of the trial were not reported, the idea of financial rewards for organ donation was
tested in an organ procurement interview study that explored 600 deceased organ donation
decision-makers’ attitudes and beliefs (Siminoff & Mercer, 2001). Almost 24% of the decision-
makers thought the idea of receiving a payment for organ donation was insulting, and around
92% of those that had declined to donate explained that even if offered financial incentives they
would still have declined (Siminoff & Mercer, 2001).

Garrison et al. (1991) used audit methods to identify that family perceptions of time and
its relational association with the determination of brain death and the request for organ donation
were important modifiable factors that influenced organ donation decisions. The two-phased
retrospective chart review study in 1988 examined 32,562 deaths in a Kentucky organ
procurement organisation (OPO) region with the purpose of accurately defining the potential
donor pool, and analysing the dynamics of the request process of family discussion. The audit
was conducted by OPO staff and transplant physicians that in the first phase of the study
categorised all transplant medically suitable deaths and found 173 potential donors, of whom 38
donated organs, 92 were donation refusals and 29 potential donors were missed. The second
phase of the study, conducted during 1989–90, identified 155 medically suitable referrals, of
whom 64 became organ donors. Analysis of the timing involved in the discussion about death
and the request for organ donation identified that when the discussion about death was
‘decoupled’ from discussions about organ donation, 53 families agreed to donation out of 93
requests (~57%); whereas when the family was told of the death and immediately requested to donate organs, there were only 11 consent decisions from 61 deaths (18%) (p. 392).

Garrison et al. (1991) reported that when the deceased held no previously known objection to donation, and when the death was ‘clearly explained and accepted by the family prior to the request for organ donation’ (p. 394), 82 requests resulted in 53 organ donations. It was recommended that to maximise consent rates, ‘family need time to understand and accept brain death before any request for organ donation’ (p. 396). The influence of relational aspects of time on the request for organ donation was an important novel finding regarding family consent to organ donation. The study provided the first confirmation that families need time to adjust to being told of their family member’s brain death before being asked to donate their organs, and showed that separating the family discussion about brain death from the discussion about organ donation could substantially increase consent rates (p. 396). This issue will be qualitatively explored with the participants in this study.

In another US study, Niles and Mattice (1996) sought to evaluate Garrison et al.’s (1991) findings regarding timing around the organ donation discussion, specifically aiming to examine how timing factored in the approach and consent to organ donation, by asking Ohio OPO coordinators to complete a retrospective questionnaire at the time of organ donor referral. The study was conducted on a sample of all referrals to the OPO over a 23-month period and encompassed 127 organ donation requests (Niles & Mattice, 1996). The requests were divided into three case categories: families approached about organ donation before death occurred; organ donation broached at the time of informing the family of the death; and donation sought
after the family had been told of the death. The timing of the first mention of organ donation ranged from discussions with families in the emergency room, until days later. Overall, 56% of families agreed to donate. Donation was mentioned first by family members in 17 cases, physicians in 82 cases, nurses in 23 cases and OPO staff on five occasions. There was no significant difference in consent outcomes between donation discussions held before or after the declaration of death; however, there was a reduction in consent rates when organ donation was discussed at the same time that families were informed of their relative’s death. Families were more inclined to donate when they had accepted the inevitability or presence of death. Niles & Mattice recommended that families of dying patients should be prepared and educated about signs of death and organ donation choices while the death is impending and before discussion. This small study contributed further evidence regarding grieving families’ need for sensitivity in the timing and provision of information about organ donation; issues that will be explored in the current study.

Death audits conducted in the UK to determine the potential for organ donation and to devise strategies to ‘convert’ potential into actual donors produced similar findings to US audits, concluding fewer potential donors were identified than had been predicted based on death rates. One such audit of all ICU deaths in England (24,023) and Wales (682) was conducted from 1989 as a two-year prospective audit supported by the Department of Health (Gore, et al., 1992). The study took place at a time when legislation to mandate that health professionals request organ donation was being considered. Gore et al. (1992) sought to determine the potential for solid organ and corneal donation, organ donor rates, regional variation in reports of brain stem death, and the number of family donation refusals. The finding that families were asked for organ
donation in 94% of brain stem deaths suggested that it was unnecessary to introduce legislation to mandate donation requests. Further, the potential for organ donation was smaller than previously thought and could be maximised by performing brain stem testing in all patients that appeared brain stem dead and by seeking consent to donation. A 30% family refusal rate was the biggest factor limiting organ donation in England and Wales, but the refusal rate declined by 25% coinciding with a transplantation public awareness campaign, suggesting that advertising influenced family consent (Gore et al., 1992). However, other studies have reported that public campaigns are ineffective in increasing donation rates (Domínguez-Gil et al., 2010; Verbal & Worth, 2012). This idea is supported by the fact that the recorded consent rate to organ donation has decreased over time in the UK despite years of public campaigns targeted at increasing organ donation, and the 30% refusal rate reported by Gore et al. (1992) is substantially lower than the current rate. Australia continues to utilise public campaigns with the objective to increase consent to donation, and yet the consent rate remains effectively unchanged, suggesting other factors may be at play.

A large study by Gortmaker et al. (1998) was premised on the view that ‘the greatest impediment to organ donation is the refusal to consent’ (p. 210). The study examined three factors that might increase consent rates in the US: decoupling the request, using specialist coordinators in the donation request, and requesting donation in a private setting. Data relating to 1,261 medically suitable potential organ donors, referred from 124 hospitals in three OPOs, was collected in1991–92 by OPO coordinators. Information about patient demographics and the site and process of the request were analysed statistically using a ‘request process scale’ that scored the presence of a decoupled request, a private setting and OPO involvement. The overall finding
of 62.2% consent to donation was analysed further, identifying that a combined process consisting of a decoupled discussion in a private setting and involving the health care team with OPO representation produced a 71.7% consent rate, which in 1993 closely matched Spain’s consent rate of 75%. Gortmaker and colleagues concluded that the US could substantially increase its organ donation rate by using a systematic approach to address these three factors, and incorporating a model and quality initiatives such as those employed in Spain. The study provided new information about the use of a systematic approach to manage organ donation requests, and revealed the important contribution of quality improvement programmes in improving outcomes.

Much of the information used to inform practices used to approach and request organ donation from bereaved families and to identify their needs has come from surveys conducted by OPOs or others with a vested interest in increasing organ donation rates. Therefore, the findings are potentially biased towards supporting the goals of transplantation and in demonstrating organisational achievement. Further, data collection has frequently been performed by personnel involved in the donation process, making such information less credible than independent reviews. Surveys often receive responses from families that have agreed to donation and seek to affirm their decision, but rarely from non-donor or disenfranchised families. Despite these limitations, data from these surveys have often been the best available evidence to give insight into families’ experiences and the factors that influence their organ donation decisions.

A survey study was conducted to ‘determine donor families overall feelings about the organ donation experience’ (Bartucci, 1987, p. 306) that would inform nursing practice, because
the author had identified that there was a paucity of research about donor family needs and experiences. The study was premised on gift theory and Bartucci (1987) argued that donor families are the best advocates for organ donation because they ‘view donation as the highest form of charity—the ultimate gift of life for another person’ (p. 306). The study was conducted following the introduction of laws that mandated US health professionals to ask all families of potential organ donors for their consent to donation, a practice known to cause ethical distress for some professionals who feared that their request for donation would intensify the families’ grief (Morton & Leonard, 1979). Working in collaboration with an OPO, Bartucci pilot tested the 11-item survey and then distributed it six weeks after the death of the donor to a convenience sample of 41 families that had donated their relatives’ organs at a US university hospital. The response rate was 83% and content analysis determined that 85% of respondents believed donation was ‘something positive in their grief’ (p. 307). Bartucci found that families that knew their relatives’ wishes and sought a positive outcome from the situation found it easier to agree to donation, and some found comfort in knowing their relatives’ organs ‘will be alive in someone else’ (p. 307). Three respondents, alarmed by their perceptions of the care given to their relatives’ body during the donation process were reported as regretting their decision to donate. Bartucci identified that families struggled with the decision-making process because the death was unexpected, some were approached by insensitive staff, and some found it difficult to agree to keep their relative on ‘life support and subject them to surgery after their death’ (p. 307).

Bartucci (1987) provided an important new finding that families suffered anguish when procedures were conducted on the body without their consent. For example, one respondent stated, ‘they went in and removed bones that I had not agreed to and in doing so severed arteries.
My son could not be embalmed, and I could not have him laid out. His four-year-old daughter was not able to see him one last time’ (p. 307). Bartucci argued that the ‘required request’ laws in the US enabled families to make autonomous decisions and have the ‘freedom to enter into gift relationships’ (p. 308), and emphasised the importance of sensitivity when assessing family needs, and care in timing the request for donation, suggesting ‘if the nurse has been able to establish trust and rapport with family members, the organ and tissue donation conversation is the first step in a recognition of the loss, the first task of grieving’ (p. 308). This study of donor family members provided further evidence that families wish to be consulted and make organ donation decisions, that informed consent and transparency in the procedural care of the deceased person’s body is highly significant to family members, and that positive attitudes to donation can be promoted while in-hospital care is provided. The process of gaining family consent for organ donation remains an ethically vexed area in clinical practice, with contemporary policy requiring the donor family to agree to a detailed list of individual organs and tissues to be donated for informed consent purposes, paperwork that some families find distressing (Thomas et al., 2009).

Processes required to gain legal consent for the removal of organs and tissue were reviewed in the UK following community outrage after a British inquiry found deceased babies’ hearts had been retained by a hospital without parental consent for research purposes (Bauchner & Vinci, 2001), and in Australia following similar scandals (Bray, 2006). The decision-making influence of administrative requirements of informed consent to organ donation and their implications for families are relevant to the current study.
An important US study by Batten and Prottas (1987) utilised a postal survey to identify the characteristics and opinions of 264 family members from around 7,000 families whose deceased family members had donated a kidney from 1982–84, drawn from a random selection process. The same survey was also conducted using a national random sample of 750 members of the general public, via telephone interviews (Batten & Prottas, 1987). The authors suggested that the donor family sample was not representative because some agencies declined to participate, record keeping was unreliable, it did not present non-responders’ views and it was not national (Batten & Prottas, 1987). Respondents to the donor family survey were disproportionately highly represented by women, and 70% were a donor parent, whereas the general public survey response was more representative of both genders. The people who responded were most influential in the decisions (35%), followed by the physician (28%), and it was found donor families use donation to construct memories and meaning from the death (Batten & Prottas, 1987).

A strongly held donor family view was that organ donation is an altruistic activity that should not be compensated monetarily, which differed from the public’s view and added credence to altruism’s role as a factor influencing donation decisions. Batten and Prottas (1987) described another important difference, that families of donors were more likely to speak about death, and donor families believed that the death is a tragedy for the survivors and not the deceased. Batten and Prottas described how families sought empathy from health care professionals, and found that families agreed to donation despite difficulty in accepting or understanding brain death. Also, families that felt in control of their situation appeared to cope better following donation, and it was suggested that families may find solace when organ
donation processes are well managed (Batten & Prottas, 1987). As mentioned previously, the standard processes of organ donation after brain death require clinical interventions to keep the deceased’s heart beating until the commencement of organ donation surgery. Batten and Prottas found that 85% of families believed that ‘when the brain is dead, keeping the heart beating is wrong’ (p. 37), and a similar proportion (79%) of the public expressed this view. Although this study was limited to kidney donors, the findings highlight public expectations and ideas of informed consent for organ donation and these factors will be explored further in the current study.

The early 1990s saw a flurry of Australian research activity examining organ donation performance. For example, Chapman et al. (1995) conducted a study to determine the potential for organ donation in nine NSW hospitals and to identify the reasons why potential donors were not becoming organ donors. A prospective audit of five hospitals was then extended to nine Sydney hospitals (Chapman et al., 1995). A chart review of 6,080 patient deaths during 1991–92 revealed 515 deaths in which a brain death diagnosis could have been possible, of which only 126 were diagnosed as brain dead, and only 112 of these being considered for organ donation. Clinicians caring for the patients at the time of death were asked to provide reasons why organ donation did not proceed or the reasons families declined donation. These reasons were recorded by a clinician involved in the study within three weeks of the event, and organ donation activity from those hospitals was also recorded (Chapman et al., 1995). Analysis revealed that organ donation may have been possible in 177 of the deaths, 49 deceased became organ donors and 63 families declined donation. Among the remaining 65 deaths, there were 14 potentially brain dead patients that had been recorded as deceased, which led Chapman et al. to suggest that treatment
had been withdrawn before brain death was confirmed. Individual hospital refusal rates ranged between 0 and 78%, with coronial processes preventing three organ donations; the deceased’s documented desire not to be an organ donor influenced 10 decisions, and 50 families declined donation. Twenty-four families provided no reason for declining donation, whereas religious beliefs, fears of mutilation and the deceased views were reported as influencing the other refusals. Most organ donation requests were made by the treating intensive care specialist, and Chapman et al. concluded a professional conflict of interest existed between ‘those whose responsibility is to care for the dead patient and their family, and those who care for the patients who are dying for lack of a donated organ’ (p. 86). The findings from this study supported those of Hibbard et al. (1992), that physicians feel conflicted in diagnosing brain death, and in approaching families about organ donation. The idea that conflict of interest may influence organ donation decision-making will be explored further in this study.

A quality improvement initiative by Savaria, Rovelli and Schweizer (1990) revealed the importance of performance evaluation and analysis, because without such surveys the experience and needs of donor families may have remained unknown. They conducted a survey between 1983 and 1989 on behalf of the Hartford Transplant Centre in Connecticut in the US with the aim of maintaining communication between donor families and the OPO. Surveys were distributed to 196 families from a sample of 206 donor families that could be traced six months after the organ donation, with a response rate of 51%. As in other studies, most surveys were completed by the mothers of the deceased. The survey comprised 14 questions that had been reviewed by transplantation experts, coordinators and a donor mother. The deaths were reported as unexpected and comprised donors aged between 6–63 years. Savaria et al. reported that 63
respondents made a decision without knowing their relative’s wishes; 36 remembered discussing organ donation with their relative, and 19 deceased had carried organ donor documentation making their wishes apparent. Most respondents claimed to understand brain death ‘but 14 did not feel they had a clear understanding even though they consented to donate their loved ones organs and tissue’ (p. 316); however, 85% of respondents believed they were asked for donation at the right time.

Savaria et al. (1990) identified that some respondents had regrets about their donation decision, and suggested that a lack of understanding of brain death or misconceptions about the organ donation process contributed to those views. Most respondents saw organ donation as a positive outcome knowing the ‘donor believed in helping others’, believing someone else would have a better life, that the deceased wishes were honoured and that the donor might ‘live on’ (p. 316). Nonetheless, respondents recommended that delays in scheduling the organ donation surgery should be addressed. Significantly, 91% of respondents requested more follow-up information about the recipient outcomes, as well as support services. Although the survey represented only donor families who responded, it identified that some regretted their decision, a finding which needs to be explored further. Savaria et al. reflected that the survey provided valuable information that could assist in improving services for donor families, and recommended that other OPOs would benefit from conducting similar initiatives.

Noury et al. (1995) conducted a survey of 100 physicians in western France that had requested organ donation between July 1992 and April 1993, to identify factors that contributed to family decisions. French legislation mandates that organ donation be sought in all cases of
brain death, but Noury and colleagues proposed that the rapport between the physician and family could influence the family’s decision. The participating physicians recorded their views regarding family responses to the question of organ donation from their brain dead relative. Fifteen families that had initially declined organ donation changed their minds after several hours and agreed to donation. This evidence for a temporal influence of the request for organ donation on the decision-maker’s capacity to reason a response, and therefore on the final decision, raises the possibility that given sufficient time more families may agree to donation after refusing in the first instance.

This is important in the Australian context because an anecdotal view suggests it is unethical to question or revisit a family’s decision, and contemporary practice generally involves a plan of care that has the treating team remove organ-sustaining technology from the patient shortly after the family has made a decision to decline organ donation. Once organ-sustaining therapies are removed there is no opportunity for a family to revisit their decision. The idea that a family may have been unable to cope with the request for organ donation or be unable to conceptualise the question and its implications is important, as it was previously identified by Garrison et al. (1991) that timing is a factor that contributes to a decision to decline the donation request. Noury et al. (1995) provide evidence that families need time to consider all the information when coming to a donation decision, and may change their initial decision to decline to one of consent; this will be explored in the current study.

One of the first large-scale studies to specifically examine the reasons why families decline organ donation was a UK study commissioned by the UK Transplant Coordinators
Association and the British Association of Critical Care Nurses, and funded by the Department of Health. Its aim was to discover why relatives of brain stem dead patients declined a request for organ donation (MORI Research Unit, 1995). A questionnaire was distributed to 338 ICUs across the UK and data were collected over a two-year period commencing in 1992. The health professionals responsible for requesting organ donation were required to complete the survey and return it after every case of brain death and when a request for organ donation was made. The survey collected details about the case, the requestor and the request, issues surrounding consent and refusal, and an explanation for the reason why consent was not sought in some deaths (MORI Research Unit, 1995).

Similarly to other death audits, this study was done without the bereaved families’ knowledge, although it did have institutional ethics approval. Of the 1,991 completed surveys, 1,214 (61%) related to an offer or consent decision, of which 515 (26%) were family refusals. Twelve % of the 1,991 families were not approached, providing an overall 62% consent rate and a 38% refusal rate. Registrars achieved consent in 57% of their requests; the consultant made most donation requests and achieved a 54% consent rate; and senior nurses received the highest refusals but were also most likely to seek consent from ethnic minority families. Higher rates of consent to a request to donate were noted in the 35–44-year-old potential donor age group, but relatives were more likely to offer donation for patients aged less than 15 years (MORI Research Unit, 1995).

In the MORI Research Unit (1995) study, family refusals to donate were associated with early approaches by inexperienced staff before the family was ready to consider organ donation;
the use of the term ‘harvesting’; and concerns that families ‘didn’t want parts alive when the rest of her body was dead’ (p.16). Twenty-four % of families indicated the deceased did not want surgery to the body and 21% stated their relative had previously indicated they did not want to donate. Twenty-one % felt their relative had suffered enough; 19% were undecided; 18% were unsure of the deceased’s wishes; 15% were fearful the patient’s body would be disfigured; some families were unable to decide; and others wanted to be present when the ventilator was switched off.

The MORI Research Unit (1995) study excluded data from 366 families who offered organ donation that resulted in 292 donations; a further six were unable to proceed due to resource limitations. This is a significant number of families and the information would have been valuable if it hadn’t been excluded, because of the paucity of research into families that offer donation. It is also important to note that many of these offers were made by the families of children. Twenty families (8%) informed staff before being asked that they did not want to donate.

Pearson, Bazeley, Spencer-Plane, Chapman and Robertson (1995) conducted an Australian telephone survey with 69 participating next of kin of patients declared brain dead in the period 1987–90 (211 cases in all). Families were invited to participate regardless of whether they had agreed to (79 cases) or declined (62 cases) organ donation by their deceased relative, or were not approached (70). The aim of the study was to assess the quality of care and information provided to the families in the ICU, and the factors that influenced their decisions and attitudes regarding organ transplantation. The experience was compared between those involved in organ
donation and those that were not. The participants were approached directly using mail and telephone strategies and a bereavement counsellor conducted the interviews approximately 28 months after the death. The survey comprised questions designed to determine the participants’ understanding of brain death, knowledge of organ donation and transplantation, knowledge of their relatives’ donation views, and details about their experience of the death and donation decisions. Of the 69 next of kin that completed the survey, 32 were from donor families, 21 had declined, and 16 were from families that had not been approached about organ donation.

Pearson et al. (1995) identified that 84% of families generally found the organ donation decision helped them with their grieving. Five families found donation was unhelpful because it contributed to pressure, family conflict and bad memories (p. 93). Eighty-five % of families indicated they had received adequate information to meet their needs, but some indicated that they did not know who to ask for more information; and 22% of families found some nursing staff ‘officious and impatient’ (p. 91). Further, some doctors were described as ‘cold and callous’ (p. 91) and 18.5% of relatives claimed ‘feeling they were in the way or unimportant’ (p. 91). Although 39 participants believed they had understood brain death before the event, of the 39, only 14 demonstrated an understanding when their knowledge was tested. Attitudes were more positive when the relative of the potential donor had made a previous decision to donate, when their relative had wanted to donate, and when they saw donation as helping others and avoiding wasting organs. Factors that influenced refusals included knowing their relative did not want to donate, spiritual reasons, belief that the body ‘should be left in peace’ and general reservations about transplantation (p. 91). No significant difference was found between the experiences of each of the groups that responded.
A disparity in the US between the rate of deceased organ donation consent (50%) and the proportion of the public that wished to donate their organs (69%), prompted a structured interview study of donor and non-donor families involving the US Department of Health, Harvard University and three OPOs (DeJong et al., 1998). Its objective was to gain an insight into bereaved family experiences, to define features of the organ donation request process, and to identify other factors associated with consent to organ donation. The sample consisted of 378 medically suitable potential organ donors referred to the Delaware Valley Transplant Program, the New Jersey Organ and Tissue Sharing Network and the New York Regional Transplant Program, from February to September 1994. Families were contacted four to six months following the death of their relative and asked to participate in the study, with 102 of 160 donor family members and 62 of 218 non-donor families agreeing to be interviewed. The survey was completed via structured telephone interviews lasting 30–60 minutes. The instrument included questions about the quality of care provided to the deceased patient, how and when the request was made, and the attitudes, wishes and characteristics of the donor and their family. Families were influenced to make consent and refusal decisions by the desire to honour their relatives’ wishes. Further, in many non-donor cases a ‘bond of trust between the family and healthcare provider was never established, leading the family not to donate’ (p. 21). DeJong et al. suggested that health care professionals should specifically address the information and emotional needs of families to enhance trusting relationships, pointing to Spain, which had formalised procedures for educating, monitoring and evaluating health care providers that contributed to it having the highest rates of donation in the world. The use of similar protocols involving frequent communication, honesty, sensitivity in timing of discussions, and privacy and accountability in practice was thus recommended.
Siminoff, Gordon, Hewlett and Arnold (2001) identified further factors that influence donor family decisions when they conducted a mixed methods study of family members, healthcare professionals and OPO staff from nine hospitals over a five-year period (1994–99) utilising chart review and telephone interviews. A 47.5% consent rate was reported in this study of 11,555 deceased patient records, which were refined to specifically focus on complete chart and interview data relating to 420 potential organ donors, of whom 238 became donors and 182 families declined. In response to an invitation, 92.5% of health professionals and 74% of decision-makers (comprising 84.7% of the donor families and 63.6% of the non-donor families) participated in interviews. Most deceased were male, white and around 40 years of age; 66.4% of decision-makers were female. The study revealed that a family’s initial response to a request for donation predicted the final outcome: 80.6% of families that initially supported the idea subsequently allowed donation to proceed. Factors related to donation decisions before the events leading to the death, and associated with consent included ‘pre-request’ variables such as family attitudes, beliefs, demographics and known wishes of the deceased. Although the authors found no effect of health care professionals’ attitudes towards donation or the hospital environment, they did find that consent to donation increased when professionals were comfortable answering family questions about donation, and socio-emotional and communication issues were important. Interestingly, no association was found between the timing of the donation request, the discussion regarding death and consent to donation. Rather, Siminoff et al. emphasised that there was no effect on the rate of consent or the belief that the patient was alive for families who knew their relative had been declared brain dead. Resulting recommendations, included educating health professionals to assess the family’s understanding regarding the prospect of their family member’s survival, and also preparing and educating the
public regarding the process of organ donation. The study provided a significant contribution to US policy and practice in organ donation.

Another large US study specifically sought to develop a questionnaire tool to determine family attitudes, decision-making factors and predictors for deceased donation (Exley, White & Hoot-Martin, 2002). The instrument was developed based on information drawn from interviews with four families that had declined deceased organ donation, along with the insight and experience of OPO staff and literature sources. The survey comprised groups based on five factors: trust and caring, religious beliefs, decision doubts and conflicts, transplant beliefs, and pain and mutilation (p. 45). The survey was distributed to 545 donor and 201 non-donor families that had been asked to donate organs, by OPOs in six states, at least four months after the death. There was a response rate of 55% for donor families and 19% response for non-donor families. The low non-donor response prompted the offer of an incentive of $25 to non-donor families to encourage increased participation, which was subsequently increased to $50 in a follow-up survey that resulted in 19 additional responses.

The results revealed significant differences in the donor and non-donor group responses in ethnicity, religion, the professional background of the person that initiated the request, the cause of death, presence of a donor card, and timing of the request (Exley et al., 2002). Non-donors had longer time between their injury and the request than did donors, which suggested that prolonged time in hospital increased donation refusals. Families claiming no religious affiliation were less likely to donate, whereas when gunshot or suicide had caused the death 98% of families agreed to donate. These findings are similar to those of Siminoff et al. (2001) who
found that trauma victim families are more likely to agree to donate. Donor families requested greater sensitivity from health professionals, more recipient information and as in earlier studies (Savaria et al., 1990), wanted the organ recovery process expedited once they had given approval.

Non-donors commented on clinical practices involving their loved one and reported a lack of compassion from health care staff (Exley et al., 2002). Unlike Siminoff et al. (2001), Exley and colleagues identified that time played a relational role in family decisions, noting donation rates were higher when organ donation was mentioned prior to the pronouncement of brain death, and when linked to family discussion about organ donation before the confirmation of death. A signed donor card was found to be important affirmation of the deceased’s wishes and family members tended ‘to default to no’ (p. 51) when a card was not present. Families wanted to spend more time with their relatives and to consider their options. This study presented a new perspective on family decision-maker attitudes and suggested that time is important and nuanced in its interpretation and its relationship with the declaration of brain death and family decision-making.

A study conducted in two Spanish hospitals from 1998 to 2003 examined 268 consecutive requests for organ donation that were made to the families of patients assessed as eligible to donate (Frutos et al., 2005). The data were separated into donor and non-donor responses and analysed using a 52-item tool. The sample was divided into 211 families that agreed (of which 21% spontaneously offered donation) and 57 families that declined donation. Families that offered donation or were knowledgeable about the process of declaring brain death
were more likely to consent. In contrast, families that declined donation were concerned about either maintaining their relative’s bodily integrity, honouring the deceased wish not to donate, did not accept brain death, had socio-cultural reasons, had a poor view of the health care provided, or had religious reasons. Frutos et al. argued that there are multiple factors that can influence the family decision and ‘the interview for organ donation must be seen as a process that starts the moment the family arrives at the hospital, receives medical information, and forms an opinion about the medical performance’ (p. 1558). They also suggested that the interview with the family should be planned by the transplant coordinator, to ‘minimize improvisation’ (p. 1559).

Since 1996, five national surveys of donor families have been conducted by the Australasian Transplant Coordinators Association (White, 2008). The most recent study included questions for families that had experienced the organ donation decision-making contexts of DCD as well as DBD (White, 2008). Members from 134 families that agreed to organ donation in 2006 responded to the survey and indicated they had received a high standard of care, consistent with the findings from previous surveys in Australia. Open-ended responses to the survey questions provided qualitative data themes that were similar to the results of previous surveys and highlighted the importance of sensitive communication, a desire for communication from recipients, a need to understand information given to families, privacy and support for the family, and that family members derived benefit by having ongoing contact with the organ donation agency. The sensitive nature of the studies reported by White (2008) meant that representatives from the organisations that provided the organ donation service selected participant families that they believed would be comfortable to receive an invitation to
participate, and would not suffer additional distress by receiving the invitation. This process may have excluded families that were unhappy with their experience of deceased organ donation, which is a significant limitation of these studies. Nonetheless, their findings were used to inform the content and conduct of the Australasian Donor Awareness Program Training (ADAPT), which is used to teach doctors, nurses and allied staff about brain death, organ donation and communicating with families about death and organ donation in Australia (National Task Force, 2008). At the time of the current study, the effectiveness of ADAPT education in achieving consent for organ donation had not been evaluated, in Australia or elsewhere.

The idea that an individual’s autonomous wish to donate is the strongest predictor of a consent decision at death has provided impetus for research into understanding what inhibits individuals from designating themselves as an organ donor on consent registries. It is possible these studies may also provide insight into barriers to donation for families that make deceased organ donation decisions. A multi-site qualitative dyad study conducted by Morgan, Harrison, Afifi, Long and Stephenson (2008), and funded by the US Health and Human Services Administration’s Division of Transplantation, recruited 78 families via a campus newspaper and a $40 financial inducement to participate in a 90-minute videotaped interview. The sample comprised 33 partner–spouse dyads, 30 parent–adult child dyads and 15 ‘other’ relationship combinations that included participants with diverse ethnicity, gender and education characteristics. In 38 dyads, both participants carried donor cards; in 13 dyads neither participant carried a donor card; and in 27 dyads one member of the dyad had signed a donor card. The reasons that participants in this study provided in support of organ donation, included their religion or a desire to help others.
The major reason given not to agree to donation, held by 47% of participants, was a deep mistrust in doctors that included concerns about medical error, hospitals and organ allocation systems. The participants were fearful of medical mistakes in declaring death, including the premature declaration of death for the purpose of organ donation, the black market organ trade and ideas about the deservedness of the organ recipient. A range of non-rational and visceral factors inhibited the participants’ acceptance of organ donation including the idea of the organ donation ‘ick factor’ and other negative feelings that participants were unable to name. They expressed concerns about recipients acquiring the psychological traits of the donor, fears that the donor would feel pain at the time of organ procurement or that donation violates bodily dignity, and the possibility that signing a donor card is ‘bad luck’ or a ‘Jinx’. Morgan et al. (2008) argued that the absence of information about the organ donation process in public advertising that promotes organ donation encourages an information ‘vacuum’ in which misinformation and ignorance flourish, and that when religion is provided as a reason not to donate, it may in reality be a ‘cover’ or excuse. The study concluded that it is ‘simply not enough to discuss the overwhelming need for transplants to save lives’ (p. 31) and that ‘public education must focus on the process involved’ (p. 31) and decouple death from donation.

Hyde, Wihardo and White (2012) investigated Australian community and university student views to establish if negative beliefs about organ donation were currently held by the community, and if these had changed over time. The purpose of the research was to suggest targeted areas of education to address negative perceptions of organ donation in the Australian community. A survey of 468 people established that 381 respondents saw themselves as donors, 26 as non-donors and 61 were undecided. An important finding relates to a fear expressed within
the Australian community that health care teams will be less inclined to save life, or may even take efforts to hasten death if a person has registered as an organ donor. Hyde et al. proposed that these impressions and fears are linked to a lack of understanding and information about the organ donation process, which has led to a loss of trust, consistent with the conclusions of Morgan et al. (2008) discussed above. When asked about organ allocation, the organ donation black market, and donation to ‘undesirable recipients’, 30% of ‘donors’ were neutral or held fears about these issues. Both donor and non-donor respondents were confused or concerned about brain death and family and religious support for their donation decision. However, trust in hospitals and doctors were proportionately greater in the donor group. Hyde et al. suggested that the public discourse is informed not only by the media and poorly constructed movies, but also by other families that, if provided with inadequate support in the hospital, may misinterpret their witness of death and organ donation.

Significantly, Hyde et al. (2012) found that 77% of respondents that claimed ‘donor’ status believed that ‘organ donation would not create distress for their family’ (p. 537), and 85.1% of donors responded that their family supported donation (p. 537). It was identified that 90% of the ‘donor’ respondents’ families would respect their wishes if identified on a register. A limitation of this study, as in other organ donation studies, was an unequal gender response, with 79% of respondents being female. The finding that 77% of respondents assume that the processes of organ donation would not contribute to additional suffering for their families raises the question of whether this view could have influenced the 81.5% participant response that families would support donation decisions. If, however, the decision-making family is faced with new and challenging information, or unexpected circumstances about organ donation practices
that contributed to unexpected perceptions of suffering for them or their relative, would they still be content to donate? This important question will be explored further in the current study.

2.3.2 Requesting the gift of organ donation, viewing care at end of life

In this literature review, I have included studies that are over 20 years old and may appear to lack relevance to this study. However, the findings from many of these studies remain relevant because they situate the understandings of family deceased organ donation decision-making as it evolved from the time of the first deceased donations for transplantation until the present time. The expectation that individuals and families agree to deceased organ donation as an altruistic, anonymous act performed without expectation of reward is embedded within the public discourse about organ donation, and underpins organ donation practices, policies and public promotion (Komesaroff, 2012). The idea of ‘organ donation as gift exchange’ was examined by Vernale and Packard (1990) in an attempt to explain donation decisions and the role of nurses in organ procurement. Their work stimulated discussion around whether organ donation should be publicly referred to as a *gift*, because of the sense of implied obligation that may be conferred upon organisations and recipients that accept the *gift*, and the implications these assumptions may have for donor families. The authors drew from the ‘gift exchange paradigm’ developed by an anthropologist, Mauss (1954), who proposed three concepts associated with gift exchange: the obligation to give, the obligation to receive and the obligation to repay (Vernale & Packard, 1990, p. 239). This view was examined in the context of the Judeo–Christian tradition, ‘that giving of oneself to others is the ultimate act of giving’ (p. 239). Vernale and Packard argued that the idea of gift exchange in the decision to donate has been supported in donor family research, where concerns have been revealed about the health
professional’s gatekeeper role in the ‘gift exchange paradigm’ (p. 240) when controlling the gift offered and information exchanged between donor families and recipients. In addition, Vernale and Packard suggested that complex meaning may be attributed to organ donation, arguing that more than just an organ, ‘the essence of the donor was passed on to the recipient’ (p. 141). They also proposed that if the donor family became aware of the death of a recipient of their relative’s organs, they may even experience a double loss’ (p. 240), a phenomenon I have observed in my own clinical experience.

Vernale and Packard (1990) suggested that the predominately positive view of organ donation evident in the public discourse may influence families to feel obligated to give, and yet feel conflicted if they are unaware of their relatives’ wishes or are uncertain about the donation process. Vernale and Packard emphasised that previous studies had shown most donor families seek information about the recipients, which the authors interpret as helping ‘to assure the donor families that the gift was appreciated’ (p. 240). They also discussed how a nurse’s positive attitude towards donation may influence family donation decisions. The authors recommended further research to identify how donor and non-donor families perceive the donation request, the role of ICU nurses in the organ donation process, and how attitudes differ between recipients and donor families. They also provided a context from which to understand the basis of campaigns that promote organ donation and highlight the possibility that acknowledgement and a sense of reciprocity is important for families that have agreed to donation, and the wellbeing of the decision-makers.
The idea of the ‘gift’ paradigm was challenged by Gerrand (1994) in a scholarly argument in which the author argued that the ‘gift’ is a flawed premise that could contribute to low organ donation rates, saying it would be better expressed as a charitable act. Gerrand proposed that the analogy of gift giving in the promotion of organ donation was originally conceived by legislators and policy makers who may have believed that positioning the organ donation as an altruistic voluntary gift would lead to the greatest number of organ transplantations. Gerrand’s argument opens up another level of discussion regarding the factors that contribute to a family decision to donate. However, the idea of gift exchange as sacrifice (Vernale & Packard, 1990) has not been addressed in the argument, nor has the complex meaning associated with embodiment, death and immortality attributed to the organ transplantation from deceased patients (Haddow, 2005; Richardson, 2006; Sque, Long, Payne & Allardycce, 2008). The concept of moral humility and the influence of cultural and political imbalances present in some communities may also challenge conventional views of organ donation and reciprocity (Shaw, 2010). Ideas of ‘rewarded gifting’ and the commodification of organ donation touched on by Gerrand (1994) open a discourse that touches on the levels of trust held in society about equity and the procurement of organs, and challenges the meaning attributed to donation.

The rational and relational trust between a physician who cares for a dying patient and their grieving family is delicately balanced, especially when a request is made for deceased organ donation, which may be perceived as a gift or charity in the view of the community, but may be imbued with different meanings to the requestor and ‘giver’. Tymstra, Heyink, Pruim and Sloof (1992) conducted a seminal qualitative study that explored the experience of bereaved
relatives that granted or declined permission for organ donation in the Netherlands, where legislation requires health professionals to seek family consent for organ donation from brain dead patients. The purpose of the study was to find ways to reduce the refusal rate of around one-third, and to increase the availability of organs for transplantation. The sample was randomly selected and comprised 15 families that had been asked to donate in the previous 12–24 months. Five donor and six non-donor families were interviewed utilising an open-ended check list encompassing the themes of death, the approach for donation, hospital experience, decision process and related experiences. The findings revealed the effect of the unexpected nature of the event on participants, for which ‘periods of hope had alternated with periods of despair’ (p. 142). Tymstra et al. reflected on the dilemma of the physician donation requester as ‘life saver who then changes into organ collector’ (p. 142).

Tymstra et al. (1992) identified the problem in communicating the diagnosis of brain death, and the confusion for patients’ families when brain death is described in terms such as ‘97% of the brain is damaged’ (p. 142). Poor communication regarding the time of death was identified as a factor that contributed to misunderstandings about brain death, and the authors emphasised the importance of allowing the bereaved to have time to come to terms with the diagnosis, and the importance for the family to have a trusting relationship with the physician. Some families regretted their decisions to agree, and others regretted declining; however, overall, the decision to donate was viewed positively. This important qualitative study provided a much-needed insight into the experience of both non-donor and donor families.
Pelletier (1992) also conducted a qualitative study to explore the donor family experience of stressful events during the organ donation process, to identify the greatest stressors for families in the process, and to help nurses develop strategies to care for families experiencing these circumstances. This study used a theoretical framework based on Lazarus and Folkman’s stress and coping theory, with the author emphasising that there was a dearth of research into donor family experiences, when explaining that no previous study had used a theoretical basis for analysis. Pelletier recruited seven families represented by nine participants that had consented to organ or tissue donation for a relative from the New Brunswick region of Canada in 1988, and conducted semi-structured recorded interviews in their homes. Pelletier used the terminology organ donation to encompass corneal donation when reporting four families had agreed to the donation of organs and corneas, whereas three families donated corneas. Content analysis identified that families needed more information, and that waiting, uncertainty, insensitive staff and restricted access to their relative contributed to their stress. All participants were unprepared for the diagnosis of brain death and found consenting and waiting for donation was very stressful. The author found that participants suffered significant additional stress when not asked to donate, when having insufficient information to know whether their loved one could donate, and when staff failed to respond to their offer of donation. Families wanted to know which organs and tissue were to be donated, to view their loved one following surgery and to be told the outcomes of their donation. Five families offered donation and were satisfied with their decision because they knew their loved ones’ wishes. This small exploratory study provided further new insights into the experiences and stresses facing families when making donation decisions. Importantly it revealed that the terminology ‘organ’ and ‘tissue’ donation is used.
interchangeably despite involving different procedural requirements, and this may cause confusion.

Pelletier analysed the same interview data in two additional studies. The first used descriptive analysis to identify needs of family members that may have been ‘overlooked’ (Pelletier, 1993, p. 152), and affirmed that families appreciate being asked about their experiences. Family members described how they hoped to help others, but found their information needs remained unresolved unless they asked specific questions. Families needed time to process information, to be with their loved one, to receive emotional support and follow-up information. As reported by Pelletier (1992) and other authors such as Morton and Leonard (1979) and Fulton et al. (2002), families need to make the decision, with one respondent saying, ‘I don’t think I could have lived with knowing that I hadn’t fulfilled his wish’ (Pelletier, 1993, p. 154). Pelletier (1993) suggested families see nurses as ‘being the most helpful health professionals in providing information and emotional support’ (p. 156). Pelletier (1993b) utilised Lazarus and Folkman’s (1984) theory of stress and coping to analyse the types of emotions used by the families to conclude that depending on the information content, information either contributed to, or reduced family stress. The shock of the declaration of brain death led to disbelief, numbness, anger and sadness, and agreeing to organ donation was seen as a way to cope or ‘to bring a lot of joy’ (p. 69).

Although it was known that confusion about the meaning and diagnosis of death using brain death criteria existed within the public and for families making organ donation decisions, there was no definitive evidence of its influence on decision-making until a seminal study was
conducted by Franz et al. (1997) that examined how an understanding of brain death might affect a family decision. Three US OPOs collaborated with researchers from the Harvard School of Public Health to contact 378 potential donor legal next of kin that were English speaking and adult, four–six months following deaths that occurred between February and September 1994. Recorded telephone interviews lasting 30-60 minutes were conducted with 102 donor relatives, which was 84% of those that agreed to be interviewed, and 62 (58%) of non-donor families that agreed to be interviewed. Reasons for non-participation in the study provided by donor and non-donor relatives were similar and included 36% that found talking about the death too difficult; 53% that stated they did not wish to participate or hung up the telephone and 11% that stated they objected to transplantation.

Demographic profiling indicated that those from minority and lower socioeconomic groups were less likely to donate (Franz et al., 1997). Questions relating to the respondents’ understanding of brain death and their memory of the experience revealed that 61% of donor and 53% of non-donor families could remember being given an explanation of brain death, being present during the testing or being provided with resources to help them understand the concept. Eighty-three % of donor respondents believed they had sufficient time to understand the diagnosis of brain death, compared with 56% of non-donor relatives. Although 95% of donor and 97% of non-donor relatives stated their deceased relative was brain dead, further questioning revealed significant confusion within both groups, with the finding that 52% of non-donor respondents indicated that it is possible to recover from brain death, whereas 14% were uncertain. The study found that non-donor relatives were less comprehending of brain death than donor families; however, the authors emphasised that other factors also influenced the decision-
making process. Importantly, the authors concluded that ‘families understanding of brain death can no longer be judged merely by their ability to state, ‘My relative is brain dead’ (p. 18).

Franz et al. (1997) provided recommendations for a new protocol to be used when discussing brain death with family members, which included the provision of frequent concise information updates regarding the progress and care of the patient, a limit on the number of professionals involved in communicating with the family about brain death, allocation of time for questions, care in communication when discussing brain death to make it explicit the person is dead, using clear language and visual aids to assist understanding, and elimination of inaccurate use of ambiguous phrases such as life support in order to clarify the meaning of brain death. Many of these recommendations have formed the basis of contemporary protocols used by health professionals when requesting organ donation.

The process of decision-making and the bereavement needs of families that had made deceased organ donation decisions became the focus of a three-year longitudinal study conducted by Sque, Long and Payne (2005) in the UK. A sample of 49 family members that had participated in deceased organ donation discussions was recruited to the study. The 46 donor family members from the sample participated in three face-to-face interviews over an 18-24 month period, and they also completed the Beck Depression Inventory II and the Grief Experience Inventory. The three non-donor family members participated in one interview and did not complete the psychological surveys. Sque et al. (2005) found the distressing contextual elements of the decision-making situation made it difficult for families to cope with the information and manage the needs of their dying relative and family. Factors that supported
donation were the known wishes of the deceased, the family’s positive attitude towards donation, a positive perception of the hospital care and a view that the ‘staff had done their best for the deceased’ (p. 544). In contrast, families that declined donation were unsure of their relatives’ wishes, had a poor understanding of the clinical situation, a poor rapport with the staff, believed more should have been done to save their loved one, and had families that expressed negative views about donation. The authors found that over time the implications for families that remained confused about the events and processes around the death and donation contributed to subsequent grief. Sque et al. emphasised the role of nurses and donation coordinators as being ‘pivotal to the families overall experience in the ICU’ (p. 544), noting decision-making was aided when staff were knowledgeable about the donation process. They recommended that the information and emotional needs of families should be assessed and addressed from the time of admission onwards based on their findings that families’ ongoing bereavement needs were directly attributable to their perceptions of care in hospitals. Although this study had a small non-donor family sample it does provide a valuable insight into the family experience of decision-making and its long-term implications.

The idea that the quality of care provided to a dying patient and their family may be an influencing factor in organ donation decision-making was explored in a survey study by Jacoby and Jaccard (2010) over a six-year period, involving six US OPOs. The study aimed to explore family perceptions of care during the deceased organ donation decision-making process. The study comprised 326 families that had made deceased donation decisions, and aimed to determine the interaction between those perceptions and the decision. Approximately 10 months after the death and request for organ donation, family members were invited to participate in the
study and were offered $50 for their involvement. One hundred and ninety-nine respondents representing 154 donor and 45 non-donor family members participated in a 65-item structured telephone interview during which demographic characteristics of the decision-maker and the deceased were recorded, along with the respondents’ perceptions of the social, emotional and informational support and care witnessed and experienced throughout their decision experience. The survey was pilot tested by selected mothers of organ donors. Statistical univariate analysis and multivariate logical regression were utilised to identify predictors of donation decisions and differences between donor and non-donor families. Jacoby and Jaccard identified that 90.3% of donor respondents agreed that they would make the same decision again, whereas only 57.8% of non-donors held the same view and found it more difficult to come to a decision. The wishes of the deceased did not influence the decisions; however, a formalised record was more likely to lead to donation. The respondents’ satisfaction with the provision of emotional support, support for basic physical needs, information about their relatives’ condition and information about brain death and organ donation were represented by those who had agreed to donation.

According to Jacoby and Jaccard (2010) the findings showed that families need ‘a convergence of informational and emotional support’ to agree to organ donation and that compassion, dignity and the use of palliative care principles are pertinent in the bereavement (p. e58). They argued that families may rely on friends or other intermediaries when seeking to address their needs, although the nurse and medical professional caring role appears well suited to address these needs of ‘compassion, respect and dignity’ (p. e59). The authors concluded that families that agree to deceased donation need emotional and informational support about their relatives’ condition to guide their decision-making, and that they benefit from information
regarding the processes required for determining brain death and facilitating organ donation. Similar to other studies, a limitation of this study was that it was retrospective and the demographic profile was weighted towards respondents from white, donor and female demographics; however, the study has contributed greater insight into the family deceased decision-making experience.

In Sweden, despite a system of presumed consent, refusal rates are approximately 40–50% and donation is requested by the treating physician in the ICU (Sanner, 2007). Sanner conducted a qualitative study to explore relatives’ and physicians’ perceptions of cases where organ donation had been requested, and the factors that influenced their decisions. The sample from one region in Sweden comprised 20 families and 25 intensive care physicians involved in 25 cases. Individual interviews explored the staff–family contact, perceptions of care, understandings and attitudes about death and organ donation, the approach to donation and factors influencing the decision. In some cases, the physicians had difficulty remembering the cases, whereas the families described ‘in detail what happened before hospitalization, during the hospital period, at the death, and afterward’ (p. 298). Analysis was performed using an immersion–crystallization method (p. 298). The families reported the deaths were unexpected, but that they received frequent, useful information that helped them understand the dire nature of the situation, with approximately half the respondents reflecting that the prospect of death was better than existence as ‘a vegetable’ (p.299). Bereavement was central to the families’ experience and signs of stress and crisis were evident (p. 299).
The study identified that the physicians saw their role as focused on determining death; however, some revealed ambivalence about diagnosing death, and two physicians argued angiography should be included as a compulsory test (Sanner, 2007). Despite having positive attitudes towards donation, some physicians revealed their personal wish not to donate, citing reasons that included not wanting to sacrifice their body or lose their identity if donating the heart and cornea, and disgust at the surgery. A significant finding was that physicians that request donation may fail to understand that the family that responds with no, may in fact be incapable of making a decision at that point. The study also showed that the attitude of the physician was central in obtaining consent, with only those with a pro-donation stance able to secure consent when families were uncertain of the deceased’s wishes. Sanner recommended that ‘physicians who do not have a pro-donation approach should perhaps be excused from this task’ (p. 304). Although this was a small study, its findings are relevant to the Australian context where the treating doctor usually seeks consent for donation. The finding that only pro-donation doctors were successful in obtaining consent from ambivalent families may help to explain the high donation rate in Spain, where only pro-donation doctors or nurses request organ and tissue donation without the support of public campaigns.

A Swiss multicentre study exploring the family experience of the request for organ donation was conducted by Kesselring, Kainz and Kiss (2007). The study used a qualitative grounded theory approach to interview 40 relatives of 30 brain dead patients, 5–17 months after their relatives’ death. Kesselring et al. (2007) had identified the ‘narrow focus in the literature on increasing organ donation’ (p. 211), and expressed concern regarding the long-term consequences for families of brain dead patients that had experienced organ donation decisions,
and wanted to examine whether events in the experience were seen as helpful or traumatic for those families. The authors classified the findings into seven stages that all families were noted to experience: being confronted with their relative’s deterioration; receipt of bad news; confrontation with brain death and the donation request; making the decision; family perceptions of health professionals’ behaviour; relatives’ memories; and traumatic memories. Kesselring et al. noted that ‘although brain death and organ donation are different issues, relatives perceive them as inseparable, both conceptually and emotionally’ (p. 213). When a family group responded uncertainly to the request for organ donation, the patient’s wishes, although noted, were not always supported and family refusals were linked to concerns about the deceased bodily integrity. Kesselring et al. noted that both donor and non-donor families attributed meaning to the heart and eyes, ‘the heart as centre of the person’ (p. 214) and evinced concerns about the personal qualities of possible recipients. This confirmed previous findings regarding the primacy of deceased wishes and the influence of positive attitudes towards donation. The study also contributed new knowledge that poor relationships between health professionals and families can create traumatic memories of the donation request, and that ambivalent decision-making responses can lead to traumatic memories and post-traumatic stress disorder (PTSD). The authors recommended a person, not organ-centred approach to communication with family of a brain dead relative.

A qualitative study conducted in Athens by Bellali, Papazoglou and Papadatou (2007) explored the decision-making process of parents of brain dead children that had been asked to donate their loved one’s organs and tissues. The aims of the study were to understand how bereaved parents experience their child’s care and death, how relatives reached a decision and
the factors that influenced their consent or refusal decision. The study was conducted in two Paediatric ICUs between 1995 and 2002, during which 393 children died, of whom 60 were diagnosed brain dead. A convenience sample of 22 parents of 14 of the brain dead children participated in the study 8–80 months after the death. Bellali et al. conducted open-ended interviews and encouraged families to describe their experiences, including the request for organ donation, their decision, and factors that influenced that decision.

A grounded theory methodology was used to guide the study and to develop a model to explain parental bereavement following consent or refusal of organ donation. Parents were the primary decision-makers; however, extended family played a significant role, and decision-making was collective. Also, ‘significant others play a key role and affect consent and refusal, whether parents acknowledge it or not’ (p. 447). The findings from this small sub-study came from a larger study on parental bereavement, and suggest that contrary to previous findings, most decisions to donate were based on rational stepwise processes that link to an acceptance of ‘no hope’ (p. 444) when compared with the non-donor decisions that were spontaneous ‘because they refused to accept the finality of their child’s death’ (p. 443). The instantaneous decision was reported as being a decision ‘you decide with your soul. It is not something you think about. It’s something that emerges from you’ (p. 443).

Bellali et al. (2007) reported on a novel approach successfully used by the health professionals in their study to request organ donation, which involved an ‘indirect approach’. Following the declaration of brain death, some hours would pass, and personnel would approach a family friend and informally suggest the idea of donation, which gave the family time to
consider the idea before being formally approached by the doctor. Most study families that donated were approached in this way, unlike families that were approached directly and declined organ donation. The meaning behind a decision to donate was seen to influence consent decisions and included the ideas of altruism, a desire to keep the child alive and the presumption the child would want to donate. A fear of killing the child and of mutilating and disrespecting the body negatively influenced donation decisions, and altruism appeared irrelevant in some refusals where perceptions of ‘injustice in the unnatural and untimely death’ (Israeli cited in Bellali et al., 2007, p. 447) and family suffering influenced refusal decisions. Bellali et al. concluded that trust between the family and health professionals influences bereaved family organ donation decisions, which will be examined in the current study utilising the construct of trust.

2.3.3 Exploring deceased organ donation decisions through the lens’ of the decision-makers

Research exploring the family experience of deceased organ donation was first conducted and published many years after organ transplantation from deceased donors had been instituted as a successful therapy for organ failure. Fulton, Fulton and Simmons (2002) in a seminal study, drew from a sample of 19 families of 19 deceased patients that became organ donors at the University of Minnesota Hospitals prior to May 1972. Fulton et al. (2002) recruited 14 families that agreed to participate in unstructured interviews, transcripts of which were then descriptively analysed. The most important finding from this study was that organ donation helped most families give meaning to an otherwise meaningless death, a finding closely linked to a desire to honour their relatives’ wishes. Decision-makers that exhibited empathy for recipients found it easier to agree to donate, and some felt the donation gave a sense of immortality that contributed to an acceptance of organ donation. The unexpectedness of the event, confusion about brain
death and the approach and terminology used by physicians when requesting organ donation negatively influenced the family experience, with one participant claiming it was ‘almost like stripping a car’ (p. 361). Sensitivities about time and timings of events contributed to participant distress, as did not being able to be present when the heart stopped beating, plus administrative errors. A refusal to relinquish hope for their relatives’ survival was also identified as a barrier to donation. The construct of hope will be discussed in Section Three of this chapter.

The difficulty that donor families encounter when a relative dies but their heart continues to beat and the needs of donor families before and following organ donation surgery were revealed for the first time by Fulton et al. (2002). Information about the number and experience of families that declined organ donation in the same period is unavailable. The study was specific to donor families of brain dead ‘heart beating’ kidney donors from the mid-western US and clinical practices have since evolved; nonetheless, the findings remain relevant because they provide insight into the previously concealed family experience of deceased organ donation decision-making. The findings remain relevant to contemporary practice because they point to similar factors found in more recent studies that influence bereaved family organ donation decisions, which will be discussed further.

Concern that health care professionals were hesitant to request organ donation from grieving families for fear of worsening their distress led Morton and Leonard (1979) to conduct a study to examine the effect a request to donate a dying relative’s organs has on the family’s experience of grief. The potential sample comprised family members of 40 potential donors over a four-year period from Christchurch, New Zealand, of which 37 families had agreed to donate
and three had declined. Recruitment was confined to families located within the city, and of the 44 individuals or groups of individuals that were originally asked to donate in the 40 deaths where donation was sought, 32 agreed to be interviewed in face-to-face in-depth group interviews six months after the death. This included 30 families that had donated and two families who had declined. Morton and Leonard did not report how many families were asked to participate and whether the third family that declined donation fell within the convenience sample of families invited to participate in the study. Interview questions explored the participants’ experiences and attitudes towards donation, the manner in which organ donation was sought, and participants’ views of the idea of proposed legislative change to presumed consent, to remove family decision-making responsibility.

In two of the three refusals, the participants declined to donate because of an aversion to having the donor ‘cut’ and fears that organ donation could prejudice the care of the relative or contribute to their death (Morton & Leonard, 1979). Some families evinced surprise when organ donation was raised because they ‘did not know the gravity of the situation’, reflecting ‘all hope was then dashed’ (p. 240). Participants were reported as needing time between realising the inevitability of death and the request for donation, and as reported by Fulton et al. (2002) using data from the same period (albeit published later), some requestors were perceived as ‘more concerned with procuring kidneys than with the plight of the patient or family’ (p. 240). Further, six families claimed experiencing additional distress because of the time that elapsed between their decision to donate and ‘death’, and that the participants wanted more information about every aspect of their experience including explicit information about the patient’s condition. Despite the difficulties experienced by these families, the authors concluded that most
participants viewed organ donation positively, finding their attitudes were strengthened by their donation experience. Families had agreed to donation because of a desire to fulfil their relatives’ wishes, the satisfaction of helping others, and because they did not want to waste young organs. At a time when the idea of changing legislation to remove the need to ask families for donation was being discussed internationally, Morton and Leonard concluded that families were empowered by making the decision and that it should be ‘obligatory’ for consent to be sought from families (p. 241). These findings, which are over 30 years old, are still relevant today in Australia, where the issue of changing legislation to a presumed consent or ‘opt-out’ model regularly arises (Delriviere & Boronovskis, 2011; Victorian Government, 2012).

The study of Morton and Leonard (1979) used a small sample of relatives of deceased kidney donors whose death was determined using circulatory criteria, in the period before brain death criteria was accepted in New Zealand. The sample included an unusually high consent rate, possibly attributable to families only being approached to donate after health professionals had assessed that they would agree to the request. The theoretical basis of the study and methodological detail including the study dates are unreported. The study did reveal important information that has also been reported in subsequent studies (Brown et al., 2010; Jacoby & Jaccard, 2010; Sque et al., 2008; Thomas et al., 2009). It provided the first empirical information regarding the experience of families making organ donation decisions in the Australasian context and revealed significant deficits in the way the request for organ donation was approached, with the authors emphasising that the term harvesting should be expunged in ‘the spirit of humane care’ (p. 241). It should be noted that recommendations regarding the term harvest are consistent
with Fulton et al. (2002) and remain relevant today (ANZICS, 2013). The contemporary use of terminology used in discussing organ donation will be explored further in this study.

A consistent theme identified in the literature around deceased organ donation and mentioned throughout this review is the idea of immortality. La Spina et al. (1993), from an Italian transplant organisation, undertook a mixed methods study to investigate the psychological processes that influenced consent to organ donation with the purpose of increasing the donation rate. The study began with a psychologist interviewing 20 donor families, 6–12 months following the death of their relative with analysis directed towards finding homogenous areas. The second part of the study required a physician to complete a survey for each patient where organ donation was requested, collating demographic data, cause of death, relationship between family and physician, and the physician’s interpretation of the relatives’ response to communication about death and the request for organ donation. Seventy-one surveys were returned from 11 ICUs and included 54 families that agreed to donation and 17 that refused. Aside from altruistic reasons that motivated a family to donate, some families agreed to donation as a ‘quite explicit longing to keep the deceased relative alive by identifying him or her with the patients into whom the organ was transplanted’ and this was viewed as a ‘defensive mechanism against the anguish of death’ (p. 1699). The realisation that 18 of the 20 families experienced a period of crisis described as a ‘second bereavement’ approximately four months after donation, during which the perceived connection of the donor and recipient relationship appeared to be lost, was a significant finding. La Spina et al. proposed that this coincided with being unable to know of, or meet the recipients of the donated organs. Families from lower socio-cultural groups were identified as having the most difficulty in understanding brain death, with the authors
La Spina et al. (1993) concluded that emotions determine the outcomes of requests to donate the organs of relatives. They found that the fear of death was stronger than sorrow, which was an important factor for families as they undertook the decision-making process, and that ‘denial’ and ‘escape’ were defensive processes that superseded sorrow for the families in their study. They proposed that refusal to donate could be interpreted as an effort to ‘escape’ death and concluded that denial was a factor for 25% of families that refused donation and for 7% of the population of families that agreed. La Spina et al. found that for 43% of the population who declined, behaviours suggested that the idea of escape is linked to a need to ‘maintain a certain unity of the body and to bury it as soon as possible to get the event of death out of their lives and the corpse along with it’ (p. 1700). Further, families that agreed to donation displayed a ‘reaction of fearless acceptance of the death’ (p. 1700) and 36.5% of families were noted to cry when agreeing to donate whereas only 11% of families that declined cried (p. 1700). This suggests that emotional factors may contribute to the family organ donation decision, and presents the possibility that perceptions of embodiment in the donor–recipient relationship may complicate grief.

The theory of dissonant loss was proposed by Magi Sque and Sheila Payne (1996) in a seminal study that utilised a grounded theory approach to ‘describe the totality of relatives’ organ donation experience, or to suggest inductive theory that could explain it’ (p. 1360). A sample of 42 donor relatives from three regional transplant coordinating centres was invited to participate
in the study, which resulted in 24 relatives from 16 families agreeing to recorded interviews in their homes. The participants were asked to tell the story of their experience in interviews that lasted one–two hours, and an interview guide that was developed from the literature and pilot tested, was checked at the conclusion of the interview. Eleven categories emerged from the analysis and became the basis of the development of a sequential ‘model of donor relatives experiences’ (p. 1361) whereby each phase of the experience was described by particular conflict and resolution behaviours and explained as a ‘theory of dissonant loss’ (p. 1361).

Sque and Payne (1996) found that families experience a series of pivotal events when making organ donation decisions, which include a transition between ‘hope for life’ and an understanding of the salience of death. They suggested that families understand their relative’s death in various ways, saying that in order to be certain of the death one relative may need to witness brain death testing, whereas for another ‘it was almost academic’ (p. 1362). Factors that assisted families in accepting the death included seeing the brain stem testing, having it explained, and viewing the body after the donation surgery; however, uncertainty about the time of death caused disquiet. The families expressed empathy for the health professionals seeking donation and were influenced to consent if the deceased had attributes or a known wish to donate, and when brain stem death was accepted as death; nonetheless, some decisions were influenced by personal values. Factors impeding organ donation included protective fears that their relative may suffer or be mutilated, expressed as, ‘for all intents and purposes she was dead, but I did not want her to be cut about … I didn’t want her to be hurt’ (p. 1364). Families wanted information about the organ donation process, to be told when the surgery was complete, to view the deceased and to receive support in saying goodbye (p. 1365). Sque and Payne proposed that
the decision to donate influenced families’ experience of grief, and donation assisted families to cope with the death, but recommended that to sustain that benefit, families required information to affirm their decision. The findings from this study are relevant to the current research.

One reason why families are asked to specify the individual organs and tissue to be donated is because some families will only agree to the donation of select organs, an idea linked to ideas of ‘immortality’ (La Spina et al., 1993) that as mentioned earlier is relevant to the current study. Haddow (2005) conducted a phenomenological study of 19 Scottish donor family members of 15 brain stem dead patients to determine if ‘families’ beliefs about death, the dead body and bonds with the deceased’ (p. 92) affected their donation decisions. The study explored the complex meanings and associations linked with organ transplantation including the attribution of special characteristics for the organs and tissues, such as the idea that the eyes are the window to the soul. Interviews were conducted with family members recruited from a purposive sample of 46 families invited by their health care providers from three regions in Scotland from 1991 to 2001.

The interview instrument comprised general questions, questions about the donation, death, the deceased body and reasons for agreeing to donation, and the interviews were transcribed and analysed using qualitative software (Haddow, 2005). The families understood the meaning of brain stem death and ‘the majority had even had a personal realisation of death prior to medical confirmation’ (p. 108). However, Haddow noted that the participants were disproportionately over-represented by people with some medical knowledge, and identified a division between the understandings of medical and non-medical participants. The author found
medical participants had a more utilitarian view of the body than did non-medical participants, who were fearful of ‘mutilating the body or cause it some disrespect’ (p. 108). Haddow reported that four families had initially declined donation for this reason, and around one-third of participants had declined to donate corneas despite knowing their deceased relatives wish to donate. Haddow confirmed that ‘certain organs, such as the eyes, are closely associated with a person’s identity’ (p. 109) and that participants with both a medical and non-medical background attributed ideas of immortality to their relatives’ organs in the recipients, particularly when parents donated their child’s organs. Haddow concluded that ‘regardless of how clinically detached one is, or purports to be, the strength of previous social/kinship relationships can prove overwhelming, especially for parents in the present study’ (p. 110). The study was confined to selected donor families; however, it brings important new evidence about the relationship of the family with the deceased, the body and its organs, and the influence of that embodied relationship in the donation decision.

The Australian Research Council funded research aiming to develop a greater understanding of the feelings and experiences of those directly involved in the donation process to enable informed debate, direct policy and develop strategies to care for the families and health care professionals involved in the process (Pearson, Hickson, Greenwood, Robertson-Malt & Tucker, 1998). The findings from the two-staged study are important for the present study because they contribute knowledge to better understand the experience of deceased organ donation decision-making for families as well as the role of trust. The first phase involved a qualitative study to explore the experiences of donor families, nurses and medical practitioners. Thirty donor family members from 22 families of brain dead relatives from across Australia were
interviewed individually or together; 30 nurses and 15 doctors who worked in South Australian ICUs with organ donation were also individually interviewed. In addition, Pearson et al. examined discourses in the media and literature surrounding brain death and organ donation to identify and critique the range of perspectives represented. The dominant theme identified by the authors was that organ donation was a gift of life. Representation of the donor family view was mostly provided by an Australian consumer group comprising disenfranchised donor families, ‘Silent Hearts’ (Pearson et al., 1998, p. 14). Analysis of the donor family dialogue identified several themes: violated trust, which represented ‘a loss of trust, anger and feeling of being victim’ to the process; a change of allegiance, perceived when donor families saw the focus of caring and their own feelings transitioning from their loved one to caring for others; and bittersweet feelings, the idea that despite their grief, the positive view that someone else benefited (p. 14).

Pearson et al. (1998) described how their Stage One study findings created controversy within the organ transplantation groups. There were claims of research bias by individuals representing organ donation organisations, which were addressed in the report on the assumption that the interpretation of bias was related to the complainants’ positivist orientation. The authors suggested the reason for the claim was due to a poor understanding of the scientific traditions of qualitative research, and argued that the use of this approach had opened up the discussion to wider debate and had therefore led to the incorporation of more representative views of the experience. According to Pearson et al. for some participants it was ‘the first time they had heard their views expressed in a public forum’ (p. 38). They highlighted that the findings from key figures in donor transplantation organisations revealed the area as highly politicised and
suggested an organisational desire to ‘suppress representations of the donor experience that are not positive’ (p. 25). Ideas of community and organisational trust as well as rational and relational trust may influence the decision-making of families and will be discussed further in this thesis.

The second phase of the Pearson et al. (1998) study included a deeper analysis using a hermeneutic approach of interview data from the families, ICU staff and organ transplant professional groups. The findings relating to nurses’ experiences were presented as themes involving the paradox of supporting and acceptance compared with distancing and uncertainty (p. 45); whereas doctors’ experiences were centred on reasoning, obligation, watching and waiting (p. 55). The family experience was dominated by apparently negative themes of unpreparedness, watching and waiting and aloneness, which was suggested to result from the contextually difficult experience of brain death and the transfer of a loved one to the operating theatre with a still beating heart for organ donation (p. 71).

The value of palliative care knowledge and skill in caring for patients and their families at the end of life has recently been embraced in critical care units, where staff often struggle with providing quality end of life care for patients faced with inevitable death, and their families. Lloyd-Williams, Morton and Peters (2009) from the UK’s Academic and Palliative Supportive Care Study Group conducted a qualitative study to explore the emotional and communication needs of families of brain dead patients in ICUs. Lloyd-Williams et al. had identified that ‘the principles of palliative care can and should extend beyond cancer and that patients within the ICU can benefit greatly from these approaches’ (p. 660). The study involved 20 ICUs in England
and a sample of bereaved relatives of 137 consecutive cases of brain dead potential organ donors (the dates of sampling were not reported). From the sample, 29 family members participated in interviews approximately six months after the death. The transcripts were analysed using thematic coding with only one member from each patient’s family interviewed. Lloyd-Williams et al. reported four families had declined organ donation, three had enquired about donating but been refused, and 22 had agreed to organ donation. Most families were pleased with the care provided to their relative, with some noting that the heavy staff workload reduced the time available to provide emotional support to the families. Facilities for family use were appreciated when available, but were often cramped and messy: ‘I could not sit down because there weren’t enough chairs so had to stand while the doctor was speaking to me’ [Beatrice on being told by the consultant, in the middle of the family room, that her child was brain dead]’ (p. 661). Communication about brain death was sometimes insensitive, for example, ‘it was a terrible thing being told my son’s brain was scrambled’ (p. 661) and families were confused about the time of death, reported feeling unsupported and struggled when leaving their loved one’s body at the hospital. No family had been offered social worker or chaplaincy support, care was specific to the patient but not the family, and bereavement care was seldom offered. The authors recommended the use of palliative care approaches to improve relatives’ experiences and enhance communication, which will be discussed further in this thesis.

Thomas, Milnes and Komesaroff (2009) contributed to the implementation of the National Organ Donation Collaborative (NODC) in 20 hospitals across Australia using a programme based on the Breakthrough Collaborative Methodology from the US, which was designed to increase organ donation rates using quality improvement processes within hospitals
(Australian Donate, 2007). Thomas et al. (2009) wished to understand if the introduction of the model had improved the experiences of those involved in the organ donation process at the Alfred Hospital in Melbourne. The study utilised a descriptive qualitative methodology and encompassed the 12-month periods before (July 2005–June 2006) and after (July 2006–June 2007) introduction of the NODC. The sample comprised all donor families of brain dead patients and staff involved in organ donation in each of those periods. Seventeen donor family members, 11 doctors, nine nurses and five coordinators involved in the donation process were interviewed. Family interviews were conducted face to face, 2–18 months following the decision, and structured interviews were conducted face to face or by telephone with the physicians and nurses. Data were analysed using constant comparative techniques. There were no differences in the family experiences for those who agreed to organ donation before or after the introduction of the NODC.

Thomas et al. (2009) reported themes involving family dissatisfaction when they were prevented from being with their relative in the emergency department, and satisfaction with the care provided in the ICU and from donor coordinators (p. 590). Themes related to the donation process caused family concern specifically related to the prolonged times and the technical and bureaucratic nature of the process. Many families felt unsupported following the donation, and some requested greater involvement in promoting donation and more knowledge about the recipients. Staff described their experiences as ‘difficult and stressful’ (p. 592) and reported that some families were conflicted in the decision-making process. Nurses saw their role as supporting families and bridging their information and communication needs with physicians.
The NODC was perceived by staff as an initiative specifically targeted towards identifying potential donors in the emergency department and ICU (Thomas et al., 2009). Wishes of the deceased were identified as the most important factor in the donation decision and were believed to be influenced by family conversations before death. Time was required for families to understand information and was also important when setting expectations regarding the donation process time frames. This is the only recent qualitative study in Australia that has examined the bereaved family experience of organ donation. The findings that organ donation and its outcomes were stressful to all those involved will be discussed further in this study, as will the role of the emergency department.

Few studies have specifically explored the views and experiences of families that have declined organ donation. Ongoing concerns that over 40% of families declined organ donation led UK Transplant to commission Sque, Long, Payne and Allardyce (2008) to conduct a study to explore the reasons for families declining to donate their relatives’ organs. The study utilised a retrospective, cross-sectional, qualitative study methodology and recruited a sample of 26 members of families that had declined to donate the organs of 23 deceased relatives, using a national campaign consisting of media, advertising and ICU approaches. Most interviews were conducted face to face or by telephone, at least three months after the bereavement, utilising a previously validated interview guide that explored the events leading to death, hospitalisation, information about death, donation request, reasons for not donating and the implications of the decision. Theoretical analysis was conducted using constant comparison techniques, and ‘Gift Exchange Theory (Mauss, 1990), Mongoven’s (2003) and Sque’s et al.’s (2006b) ideas about sacrifice’ (Sque et al., 2008, p. 138) guided the study. Six themes were identified: protecting the
dead body; the circumstances at death; lack of knowledge; the donation discussion; witnessing end of life and views of donation.

An important but unexpected finding was the high number of pro-donation views held by respondent relatives and the deceased: 12 participants and nine deceased had been supportive of donation and an additional four were ambivalent. In six cases, despite both the relatives and the deceased identifying as being pro-donation, the family still declined, suggesting that a positive attitude was not sufficient to guarantee donation. The main reason given for refusals was to protect the body from being ‘cut up’ (p. 139). Sque et al. (2008) reported that some participants felt ‘selfish’ for declining donation, but relief when they realised they were not alone. The findings led the authors to suggest that decision-makers experience two discourses when at the bedside. The authors described that ideas of ‘sacrifice’, and the idea that their relative may experience prolonged suffering, compete with decision-makers’ ideas of agreeing to donate the ‘gift of life’, and argue efforts should be directed at alleviating this perceived conflict for families. A limitation of this study was that some participants relied on their memory of events almost 20 years before. Women were over-represented with 18 female and 8 male participants. The idea of sacrifice will be explored further in this study.

The process of organ donation following death generally takes place after the family members of the patient and the physician have reached a consensus that there is nothing more that can be done to help their family member. The events, time and relationships that have led to this point are mostly dependent on a trusting relationship with professionals caring for the deceased, so that when a decision to withdraw life-sustaining treatment is made, regardless of the
organ donation decision, the family are satisfied that their family member’s interests remain protected (ANZICS, 2013). Martinez, Lopez, Scandroglio and Garcia (2008) conducted an exploratory qualitative study to examine six donor and three non-donor families’ decision experiences. Their objective was to identify the principal psychosocial variables affecting family organ donation decisions, to analyse the interaction of these variables during the process of organ donation and to propose an organ donation decision model. Martinez et al. proposed that the will of the deceased and the family’s attitudes would guide the decision. A previously developed instrument was utilised in the interviews to take the participants through a chronological sequence of events in the decision and donation process. The sample of nine families was recruited by the transplant coordinators and comprised family members that had made organ donation decisions within the previous 3–12 months. The data were interpreted longitudinally across the events using discourse analysis and compared between the donor and non-donor families. The study revealed that families received inadequate information to understand the severity of their relatives’ condition, which led them to develop hopes that were later dashed. Further, communication with doctors who were seen as ‘cold, hard and prepotent’ (p. 134) contributed to a loss of trust and consequent refusals. The view of one participant was that listing all the organs felt like ‘my husband’s body was taken to pieces’ (p. 133). Women as mothers or wives were responsible for eight of the nine decisions. The wishes of the deceased guided family decisions, and in cases of refusals it was often external factors that influenced the decision to decline. The findings regarding the effect of stress on the family were inconclusive; however, the authors determined that the use of crisis intervention techniques by the coordinator could provide an opportunity to manage the situation more effectively by providing active guidance to the family through the donation and bereavement experiences. It was proposed that this may be done
by encouraging the family to talk about and share memories about the deceased and to engage in the use of ‘farewell’ rituals that assist the family to accept the situation. Martinez et al. recommended the skilled use of contemporary persuasion techniques for families that are uncertain of their relatives’ wishes. This study contributes further evidence regarding the family decision-making process and the influence that active intervention by the health care team may have on the family decision outcome.

The idea that families making deceased organ donation decisions seek to create a sense of peace was an important conclusion from a study by Manuel, Solberg and MacDonald (2010). The study used a phenomenological approach to explore the lived experience of five Canadian women that had donated their deceased relatives’ organs within the previous three-year period, via unstructured recorded interviews. Thematic data analysis identified seven themes that included the decision-maker’s sense of disbelief about the death; the struggle to acknowledge the death; a need to validate the deceased’s life by creating a positive outcome; the use of donation to maintain a living memory of the deceased; the finding that waiting for donation surgery ‘bought time’ before the treatment was ceased. The importance of support for the decision and the idea of the abandonment felt when decision-makers believed they had been left without support, for example, ‘you put your trust in them and then get let down’ (p. 232). The final theme encompassed the essence of the experience. The authors argued that nurses have a role in caring for families and helping them to find peace in their decision using bereavement techniques, and recommended more research into the nurse’s role in deceased organ donation decision-making.
In the UK, a systematic integrative literature review was conducted with the goal of understanding the ‘factors that contribute to bereaved families decisions to agree or to decline donation of their deceased relative’s organs for transplantation’ (Walker, et al., 2013, p. 1341). Peer-reviewed qualitative or quantitative studies from Western countries published between 2001 and 2011 were included if they described bereaved families’ subjective perceptions, decisions that related to the context of brain death or circulatory death, decisions regarding adult or child donors and sub-studies that met these criteria. Studies reporting interventions to effect behaviour change in decision-makers or perceptions held by health care staff or the public, audit or record data studies, and duplications of previous studies were excluded. The Whittemore and Knaff (2005) integrative framework was used to structure the review (Walker et al., 2013). A focused search identified 910 results, of which 20 studies were examined comprising 12 qualitative, seven quantitative and one mixed method study. Thematic network analysis (Attride-Stirling, 2001) was used to derive 18 themes that were then reduced to seven organising themes. The idea of temporality guided the refinement of the themes to three global themes comprising The Past, based on the wishes of the deceased and the attitudes of their family; The Present with foundations from intra/interpersonal determinants; and The Future, which captured ideas around the hopes and expectations of the decision-makers and the life meaning of the deceased. In discussing the findings from their review, Walker et al. accentuated how the ‘complex reality of decision-making was rendered visible, leading to the identification of a wide range of factors that clearly influenced the rate of family consent to organ donation’ (p. 1353). They concluded that the ‘multiplicity’ of factors found to influence decision-making made it difficult to draw transferable conclusions from their review. They also emphasised the importance of conducting qualitative research with bereaved families to better understand the factors that influence their
deceased organ donation decisions, and specifically identified the influence of experiences such as witnessing death and the family experience of time in the context of circulatory death, which will be explored further in this study.

It is clear that most research into the factors that influence family deceased organ donation decisions has been directed more towards findings ways to meet the transplant needs of recipients, rather than balancing the needs of dying and deceased patients and their grieving families. Interestingly, the emergence of the bioethical paradigm of ‘principlism’ (Beauchamp & Childress, 2009) coincided with the emergence of transplantation therapies and a move away from the idea of the value of life, instead focusing on a more utilitarian view of health care (Pellegrino, 2011). Although some commentators, and professionals involved in deceased organ transplantation may view this as acceptable and appropriate, the community view regarding the value of life, and care of the dead may differ. Some have suggested that community trust in organ donation practices requires a clear articulation of the value of the life, and a more balanced approach to donation advocacy (Truog, 2008).

2.3.4 Conclusion

This literature review has shown that many findings regarding the factors that influence decision-makers have remained consistent over time. Few qualitative studies exploring the experience of donor and non-donor families have been conducted, and therefore there is little understanding of the complexity of the decision-making process or of the way the factors come together to influence the final decision, which is individual to each death and to each family.
2.4 Section Three: Theoretical framework

This study will use an eclectic theoretical framework based on Weinstein’s (1988) Precaution Adoption Process Model which is a dynamic decision-making model used in health care environments. To address the aims of this study, specifically the second aim, which is to determine if hope, deep hope and trust play a role in the decision-making process, this Model has been modified to include the three constructs of hope, deep hope and trust. The construct of hope draws from ‘Hope Theory’ in which Snyder (2002), defines hope as ‘the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways’ (p. 249). This study proposes that families faced with organ donation decisions experience hope in its various forms and find ways to transfer their ‘hope for life’ felt towards their relative, to other goals. It then proposes that Deep Hope defined by Coulehan (2011) as ‘a layer of hope that underlies this experience and may continue to exist, or even thrive, during a time when the patient has very few somethings left to hope for’ (p.144) may play a role in the decision-making process. Finally, this study also proposes that trust (Job, 2007) plays an important role in allowing hope to flourish. According to Cartwright (2004, p.169), ‘human beings, then, have the power of choice, and their exercise of that power will be much influenced by their having- or not having- hope for a better future’.
### Table 2.1 Definitions of hope, deep hope and trust used in this study

| **Hope** | The definition of hope used in this study is drawn from ‘Hope Theory’ (Snyder, 2002). Snyder defines hope as ‘the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways’ (p. 249). |
| **Deep hope** | The construct of ‘deep hope’ is drawn from the palliative care literature. In this study it relates to the participant families’ deceased organ donation decision-making experience and is defined as ‘a layer of hope that underlies this experience and may continue to exist, or even thrive, during a time when the patient has very few “somethings” left to hope for’ (Coulehan, 2011, p. 144). |
| **Trust** | The definition for trust used in this study combines rational and relational trust and is defined as ‘social learned and social confirmed expectations that people have of each other, of the organisations and institutions in which they live, and the natural and moral social orders, that set the fundamental understandings of their lives’ (Barber, 1983, p. 28). |

### 2.4.1 The Precaution Adoption Process Model of Decision-Making

The decision-making process of deceased organ donation differs from decision-making processes utilised in most health models of decision-making behaviour for three main reasons. First, it involves a decision-making process which is considerably complicated as it occurs during a period of contextual uncertainty involving new and unexpected information and emotion. Second, the decision outcomes have implications beyond the individual decision-maker experience including a range of additional people such as family members and people unknown to the decision-maker. Finally, it differs because unlike the motivation which underpins the precaution adoption process which is reliant on individuals using self-protection as a motivation to act, organ donation requires a decision which may be perceived as potentially harmful to self
or family, and depends on motivations based on altruism or meaning-making to motivate decision-makers.

The theoretical framework utilised in this study was chosen because it is an appropriate fit for the complex problem under investigation (Glanz, Rimer & Viswanath, 2008). The adequacy of a theory is judged on its logic, relevance, scope of concepts, and its theoretical plausibility within the field (Glanz, et al., 2008, p.35).

Neil Weinstein (1988) has contributed to a significant body of literature on preventative health care decision-making and theories of health protection since his initial critique of models of preventative behaviour, and his development of a five stage framework. This framework was extended into a seven stage Model of the Precaution Adoption Process and analytically tested in 7 studies of home radon testing (Weinstein & Sandman, 1992). Weinstein’s (1988) decision-making model was structured around the concept that preventative health care decision-making involves balancing changing ideas of cost and benefit along with cues to action which occur over time, and with the idea that decision-making is not always based on rational factors. Weinstein’s (1988) model accounts for ideas of self-protection inherent in complex decision-making which may involve new information and require cognitive processing. The justification of the theory accounts for the decision-maker balancing these perceived risks and fears with their intentions. Weinstein (1988) suggests that the goal ‘of avoiding future harm’ (p.358) inherent in preventative decision-making behaviour, and particularly relating to the context of new and complex behaviours, requires the decision-maker to believe that they are at risk and need protection. Furthermore, they need to be provided with appropriate information to motivate them
to take preventative actions which may subsequently be assessed as effectively protecting them from harm.

Weinstein (1988) suggested that a stage theory is a most useful structure to explain precaution adoption process behaviour because it acknowledges individual variation in behaviours and motivators of behaviours over time. The five stages in the precaution adoption process model of decision-making comprise, Stage 1: Has heard of the hazard; Stage 2: Believes in significant likelihood for others; Stage 3: Acknowledged personal susceptibility; Stage 4: Decides to take precaution and Stage 5: Takes precaution. The author also proposed that it is possible that the effort to move from one stage to the next can be perceived as a barrier that ‘must be overcome before action is taken’ (Weinstein, 1988, p. 358) and that movement between stages is not linear. These stages are described in Figure 2.3.1 (p.126).
Figure 2.3.1. The Model of the Precaution Adoption Process used in decision-making (Weinstein, 1988). Stage 1 and 2 are more relevant to autonomous decision-making. Stage 3, 4, and 5 which are highlighted in blue, are particularly relevant to deceased organ donation decision-making.

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<td>1.</td>
<td>Has heard of hazard</td>
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<td>2.</td>
<td>Believes in significant likelihood for others</td>
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<td>3.</td>
<td>Acknowledges personal susceptibility</td>
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<td>4.</td>
<td>Decides to take precaution</td>
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<td>5.</td>
<td>Takes precaution</td>
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The stages explained in Weinstein’s (1988) model describe ideas of identifying ‘susceptibility’ to the threat, when he proposes that ‘focusing on familiar hazards, however, leads one to overlook the important period of time when people have no opinions about a hazard because they have not even heard of it’ (Weinstein’s, 1988, p.359). This author argued that this is a qualitatively different time from when the individual has information and experiences (Weinstein, 1988, p.361). Weinstein proposed the stages of belief relate to the cognitive acceptance of the belief and that these cognitive stages are cumulative. According to Weinstein (1988), ideas and formation of cognitive patterns occur in a ‘temporal’ manner, and when the decision-maker receives new information, they may move backward and forward within the stages and only act if the risk is perceived as significant. Factors required to address the barriers
to the decision-makers’ behaviour alter at each stage and with different influences (Weinstein, 1988, p.364).

Weinstein (1998) described the role of optimistic bias as a possible barrier to taking precautions which can be constructed from inaccurate information and inexperience; and from psychological processes around protection of self-esteem and avoidance of fear (p.363). The idea of cost was used by Weinstein (1988) to account for time and effort and the idea that the decision-maker may not be able to complete the precaution action, thus relying on the idea of self-efficacy which requires an intent and desire to act (p.365). The idea of ‘salience’ and the idea that individuals require a material understanding that there are consequences to decision-making is described by Weinstein as ‘the powerful impact of factors like vividness and concreteness on various social judgements’ (1988, p38). The idea of decision-makers being dependent on the views of others for complex problems, the effects of emotion and the idea of the ‘messy desk’ as a way of seeing shifting priorities and ‘cues to action’ (Weinstein, 1988, p.38) in taking action is important in this model. According to Weinstein (1988), when people take precautions they balance the cost using temporal influences which may include the views of others and influences such as emotions, and the absence of precaution taking leads to a prevalence of emotions of fear and anger. Importantly, Weinstein (1988) also highlights that there is a cost involved for decision-makers who act, and argues that information that can limit that cost is most useful to active information seekers, particularly when in a state of ‘vigilance’ (citing Janis & Mann, p.380), and can be seen as relevant to this study.
The Precaution Adoption Process Model (Weinstein, 1988) provides an appropriate framework with which to describe the complex and nuanced process of family deceased organ donation decision-making and may account for the cognitive processes required in managing the dynamic influence of new information, risk, emotional factors and the positioning of time. The Model can be applied to the two decision-making contexts of the decision-making process of deceased organ donation which include 1) autonomous pre-death decision-making and 2) surrogate decision-making at death by the family.

In contexts where an autonomous decision is made prior to death, it is appropriate to use Weinstein’s (1988) decision-making stages to assess the decision-readiness of the individual, their situation, knowledge and attitudes about organ donation, their fears or motivations and communication of their views regarding donation. Dynamic influences circulate through this process of decision-making until such time as the idea becomes sufficiently relevant or salient to the individual that they overcome their precaution, form an intention and make a donation decision. Alternatively they may remain ambivalent or oblivious to the possibility. If an autonomous decision is made, the decision-makers subsequent actions may include communicating their decision to donate or not donate. A decision will have required the decision-maker to address their motivations and sense of precaution regarding the risk of donation before acting to agree.

The second deceased decision context commences when the dying/deceased individuals surrogate decision-makers, the family, are faced with a critical event which ultimately results in their family member’s death and potential organ donation. During this second decision-making
context the family are required to progress through similar cognitive stages involving the idea of salience and precaution, which is complicated by the addition of new information and emotion to form a multiplicity of factors within each stage. Using Weinstein’s (1988) framework, these cognitive stages can be applied to explain family decision-makers coming to recognition of the salience of the situation and assessing precautions at stage three, then moving to stage of intention at stage four, and the decision at stage five. While Weinstein’s first two stages are relevant to autonomous organ donation decision-making, they become less important in the situation of deceased organ donation decision-making. At this time the reality of the impending death intrudes into the family’s awareness and forces an engagement with the idea, the autonomous decision and a family decision.

Therefore, the particular decision–making stages (Weinstein) that are specifically relevant to the decision-making process in organ donation comprise stages three, four and five. Stage three commences when regardless of previous circumstances, the decision-makers are forcefully made aware of the salience of their situation, and precaution may dominate as the truth of the situation becomes evident. In stage four, the decision to act requires a cognitive shift to overcome or succumb to barriers of precaution prior to forming an intention to act, and stage five represents the enactment of the decision.

Therefore, based on Weinstein’s (1988) model, decision-making in deceased organ donation decision-making processes can be explained as one that requires the decision-makers to first engage sufficiently with the idea of donation to exercise precaution to balance their perceived risks of organ donation. Second, decision-makers form an intention to agree or decline,
and third, they enact the decision, which may have a positive or negative outcome for recipients in this context of decision-making. As Weinstein (1988) points out, the decision-making process is dynamic. This is applicable to the context of deceased organ donation which is influenced by a multitude of factors (Walker, et al., 2013). The chronological sequence of events which occur for all families involved in making deceased organ donation decisions can be represented on a timeline which proceeds inexorably for the families who are caught in the progression of events leading to death, and culminate in a decision. This is represented in Figure 2.3.2. (below).

*Figure 2.3.2* The two contexts of deceased organ donation decision-making: autonomous and family decisions

![Diagram of decision-making process](image)

Figure 2.3.2 shows the two contexts of deceased organ donation decision-making: that is, autonomous and family decisions involving Weinstein’s (1988) three stages of decision-making and incorporating precaution, intention and the decision. These stages are nonlinear as shown by
the movement in the arrows. The two contexts of deceased organ donation decisions are represented on the diagram as being separated by a red dividing line. The crisis event leading to death is represented as intersecting the timeline (in pink) and the pressure of time is represented as a thick blue arrow which inexorably leads to a decision.

While Weinstein’s (1988) model is relevant to the organ donation decision-making experience, the complexity surrounding organ donation requires a more nuanced theoretical approach which more closely represents the decision-makers contextual experience of death and organ donation. Therefore, for the purpose of this study three constructs will be added to the framework that are drawn from the literature, and these will now be defined.

The role of trust and hope is mentioned frequently in the literature as factors that contribute to the experience of families of critically ill patients (Verhaeghe, van Zuuren, DeFloor, Duijnstee & Grypdonck, 2007a), and also organ donation decision-making (Martinez et al., 2008). However, to my knowledge, they have not previously been studied or contextualised in a theoretical framework to explain organ donation decision-making at the end-of-life. I have utilised the constructs of hope and trust and added deep hope to help explain the complex cognitive and psychosocial processes that influence organ donation decision-making. It is known there are multiple factors that influence the decision, and in every bereaved family experience of making such a decision, the factors will present in differing ways. I argue that rather than taking each factor separately it is better to understand and anticipate the meaning the family forms during and following their decision experience, and also what memories they anticipate as they consider their future.
The literature shows that protecting a family member from suffering and protecting their dignity by recognising their wishes is very important to the family (Sque et al., 2005). Incorporating hope, deep hope and trust into Weinstein’s (1988) decision-making model will provide an eclectic framework for this study which will not only help explain the complexity of the decision-making process across time but it will also illuminate the decision-making context of end-of-life care and organ donation processes which families transition in critical care units. The modified model incorporates the pre-existing factors present in the individual and families attitudes and knowledge of organ donation, and introduces the three constructs of hope, deep hope and trust. The model then moves in time to the event that causes death, which is when the families seek to protect their family member and use precaution to be assured they can trust the care that is provided. During this time it is proposed that if their trust needs are met, they will use hope to move through the experience, initially using hope for their relative’s survival. Once fully cognisant that death is inevitable, they will move from the despair of that knowledge to deep hope that their loved one is not suffering. Furthermore, they will draw on deep hope to bring meaning from the death which will enable themselves and their family to survive. If the family is able to have their trust, hope and deep hope needs addressed throughout the continuum of their experience, I propose they will make a decision which will align their hopes for meaning from the death with a long-term positive outcome. This proposed modified model, which is relevant to professional nursing and medical practice, will provide a meaningful framework to explore the fragile balance between autonomy and relationships in decision-making and to recognise individual vulnerability and interdependence, ideas which underpin an ethics of care (Dierckx de Casterle et al., 2011).
A diagram of the model is presented in Figure 2.3.3 (p.134) which builds on Figure 2.3.2 (p. 130). It shows an eclectic Theoretical Framework consisting of three stages of the Precaution Adoption Process Model of decision-making (Weinstein, 1988) plus the three constructs of trust (Job, 2007), hope (Snyder, 2002) and deep hope (Coulehan, 2011). The donation decision-making process consists of three key events which are the crisis event, the donation decision and the confirmation of death. Each of the three constructs is present across the continuum, but this model proposes that trust precedes hope and deep hope in autonomous and family decision-making. It is also proposed that the affirmation of expectations empowers deep hope and a decision which is generally made prior to the confirmation of death.
Figure 2.3.3. Theoretical framework using the Precaution Adoption Process Model of decision-making (Weinstein, 1988), which has been modified to propose that hope (Snyder, 2002) and deep hope, (Coulehan, 2011) influenced by trust, (Job, 2007) are used to underpin family organ donation decisions.

There are three key events which are relevant to family deceased organ donation decision-making processes. They comprise the crisis event, the donation decision and the confirmation of death.

In summary, this study proposes that families faced with organ donation decisions experience hope in its various forms and find ways to transfer their ‘hope for life’ felt towards their relative, to other goals. It further proposes that ‘deep hope’ defined as ‘a layer of hope that underlies this experience and may continue to exist, or even thrive, during a time when the patient has very few somethings left to hope for’ (Coulehan, 2011, p. 144), may play a role in the
decision-making process. Finally, the researcher also suggests that trust underpins the decisions and plays an important role in allowing hope to flourish. The constructs of hope, deep hope, and trust will be discussed in the following section to help explain the how they relate to the deceased organ donation decision-making experience.

2.4.2 Hope

‘Hope helps alleviate suffering…and often thrives even in the face of imminent death’ (Coulehan, 2011, p. 143). The role of hope has been identified as the most important need for families faced with a family member who is critically ill (Molter, 1977). Snyder, Irving and Anderson (2002) defined hope as ‘a positive motivational state that is based on an interactively derived sense of the successful agency (goal–directed energy), and pathways (planning to meet goals)’ (p.250). The assumption underpinning this work described by Snyder (2002) is that human actions are goal directed, with the goal perceived as the ‘cognitive component that anchors hope theory’ (p.250). Snyder describes agency thinking as requiring motivational thinking especially when barriers to the goal are identified when ideas of agency help ‘channel the requisite motivation to the best alternate pathway’ (p. 251). Snyder (2002) when examining pathways thinking suggests, ‘that we typically think about how we can link our present to imagined futures. Accordingly, the concept of time and how we are journeying through this continuum are necessary and useful to human thought’ (p.251). However, Snyder (2002) highlights the differences in the ability to set and aim for goals between high hope and low hope people.
Snyder (2002) proposed that emotions inform goal directed behaviours. This author identified the impact that surprise events can play upon individuals’ motivations and agency towards goals events which may be influenced by emotion. However, he suggested that despite these events, individuals are still able to adjust to the new circumstances and move forward in their pathways thinking. Snyder (2002) summarised the theory as being ‘an inter-related system of goal directed thinking that is responsive to feedback at various points in the temporal sequence’ (p.255). The association between hope and life meaning is made by Snyder (2002) who suggested that goal setting and achievement of goals is related to the meaning of a person’s life (p.262), ideas that have been tested and supported using hope score scales. Snyder (2002) argued that hope is learned and is influenced by other people throughout childhood and beyond. He highlights the relationship between loss of hope and loss of trust and the implications of hope on grief and the death of a loved one, specifically for children of a parent (Snyder 2002, p.263).

Snyder (2002) helped to explain some aspects of the decision-making process in his seminal study on Hope Theory in which he proposed a step wise model of decision-making. However, this model does not account for the moving around, and between, and back and forward, that the families in crisis experience as they pull together the information available to them. Furthermore, it does not help to fully explain the motivating power that sees some families grasp the idea of organ donation and transform in their ability to survive shock, grief and bereavement.

Verhaeghe et al. (2007a) conducted a grounded theory study of 22 family members of 16 coma patients which explored the psychological process of family members functioning during
their relatives’ acute coma. The authors identified that hope ‘was crucial in the experience of family members and dominates the processes they go through’ (p. 731) and found that their findings were consistent with previous literature relating to the needs of families of the critically ill about hope (Verhaeghe, et al., 2007a). They also found that hope was particularly linked to information and was present in every aspect of the family experience which the authors described as a stepwise psychological process. The authors discussed their finding that some family members briefly experienced signs of ‘hopelessness’ and ‘despair’ which they actively fought to overcome (Verhaeghe, et al., 2007a). The authors also identified that the families go through three phases which span the period between the accident until recovery or death in which firstly they seek to protect their loved one’s life; the second phase occurs when they seek to protect ‘themselves, the patient and the family from unnecessary suffering’ (p. 577) and the third phase occurs when they aim to protect what remains and learn to live with the outcomes (Verhaeghe, et al., 2010). This explanation was not sufficient to explain the complex family decision-making process of deceased organ donation. It was only after the researcher read the work of Coulehan (2011) on deep hope that the idea of deep hope emerged as a possible motivator and as a way to explain how bereaved families use meaning to survive the grief and separation of death while looking forward to the future.

2.4.3 Deep hope

The idea of ‘deep hope’ was proposed by Jack Coulehan (2011) in an essay examining individuals’ construction of hope in the face of imminent death. In this study ‘deep hope’ is proposed as an underpinning influence for families as they try to make the best decision possible within the confines of the death of their family member. ‘Deep hope’ is proposed as a way of
accounting for meaning in end of life decisions as family members start to recognise their new reality and structure their survival into the future. Coulehan (2011) defined ‘deep hope’ as ‘a layer of hope that underlies this experience and may continue to exist, or even thrive, during a time when the patient has very few somethings left to hope for’ (Coulehan, 2011, p. 144).

Coulehan (2011) presented an account of the application of hope and deep hope for palliative patients at the end of life which is also transferable to the experience of families of critically ill and dying patients faced with organ donation decisions. Coulehan (2011) provides insight into the possibility that the meaning represented by the concept of deep hope, may provide an explanation for the ability of bereaved families to fix on a donation decision or other hope goal in the midst of despair and transform their grief with new meaning. Coulehan (2011) describes how hope can ‘energise our existence and enable us to cope with life threatening crises, including serious and progressive illness’ (p.143), an idea that appears particularly well suited to the experience that families transition in facing the death of not themselves, but their loved ones.

Coulehan’s (2011) discussion regarding deep hope draws from the interactions between the patient and the physician as death approaches and the author reflects on the way clinicians have used hope in their communications with patients about the diagnosis of death, expectations and the prognosis of outcomes from terminal illness. The question of false hope and its relationship with trust is touched on in this discussion and Coulehan (2011) proposed that although clinicians have manipulated information in the past with the goal of preserving the hope of the patient, which was seen as a beneficent act, a better understanding of hope and its resilience and a greater emphasis on patient autonomy has changed palliative care physicians
understandings of hope. Clinicians now realise that patients benefit when provided with
information and are enabled to communicate in a more honest way about approaching death. The
idea of false hope comprises ideas of setting unattainable objectives or providing inaccurate
information which, when not achieved, leads to additional suffering for the patient and their
family. Coulehan (2011) argued that this can be as a consequence of misguided efforts ‘to shield
the patient from reality’ (146), an idea that can be applied in the context of health care
professionals and family relationships when a family faces the critical illness and impending
death of a family member.

The author identified that once the patients receive clear information with transparent
communication it enables them to focus on end of life goals that are important to them, which are
described as occurring in a fluid state in which the patient prepares for death yet continues to
*hope for the best* therefore suggesting ‘hope may endure, but its goals become more immediate
and circumscribed’ (Coulehan, 2011, p.145). This hope has been found by Viktor Frankl (2004)
as a powerfully resilient quality in situations such as the Nazi concentration camps of the
Holocaust where it could be assumed all hope would be lost, where instead, despite very few
obvious rewards, hope survived. The idea of hope having a deeper meaning and more pervasive
quality was discussed by Coulehan (2011) as he drew from the literature and developed his
argument that hope is powerfully linked to the future and is linked to life meaning, and that hope
differs from expectation, which is an outcome of a situational assessment.

Coulehan (2011) argued that hope is a complex cognitive and emotional process that
medically orientated approaches have failed to appreciate, claiming that failure to address hope
needs result in a failure to ‘address the existential core of suffering’ (p. 155). Furthermore, the ideas of a lack of interpersonal-connectedness, pain, isolation, abandonment and devaluation of the person can hinder hope (p.155). In contrast, connectedness, spiritual beliefs and practices, humanity and respect foster deep hope in palliative care practice. According to Coulehan (2011), deep hope is associated with religious practices and ideas such as affirmation of worth, trust, faith and love; however, he also proposed that deep hope may explain a more generic experience which is not necessarily reliant on religious beliefs. In conclusion, Coulehan (2011) recommends that addressing factors to meet hope needs and foster deep hope, ‘is a realistic therapeutic goal in palliative medicine’ (p.156) which I argue can be utilised by health care professionals as a goal of care for families who are facing the death of their relative and the decision-making process deceased of organ donation. If this is achieved it may help to empower families to agree to the donation of their loved ones organs.

2.4.4 Trust

Rational and relational trust have been integrated as the third construct in the eclectic theoretical framework in this study as trust underpins the ethical and legal basis of organ donation and the idea of altruistic gifting of organs for the good of others following death. Clearly, in order for family members to address their fears and be assured that their loved one is protected, they must be able to assure themselves that they can trust not only those that care for their loved one, but the institutions and organisations that arrange the donation and the long-term consequences of the decision. Doctors, other health care professionals and their associated organisations and institutions are endowed with a professional trust (Cruess & Cruess, 2014) to meet societal expectations for practices that ‘promote healing; caring and compassion, presence,
competence, and hopes for a positive outcome’ (p. 1). Perceptions of conflict of interest between vulnerable individuals and the individual professionals or organisations that are entrusted with their care diminish trust, and these interactions generally occur at an interpersonal level (Cruess & Cruess, 2014). Individual and societal trust in health care has diminished from high trust levels in the mid-twentieth century, with suggestions that medical self-interest and poor self-regulation of the profession have contributed to this decline (Cruess & Cruess, 2014). Expectations remain that all health care professionals should conduct themselves with higher standards of integrity and morality than expected of others, and that societal trust in health care organisations is dependent on individuals having their trust affirmed in their relationship with the treating professional (Cruess & Cruess, 2014).

There is extensive literature which relates to trust and its role in decision-making in the health care environment and at an individual, community and regulatory level as mentioned earlier in this thesis. Distrust also plays an important role, particularly at an institutional level in protecting the community against the abuse of power (Gilson, 2006). Health professional and patient relationships are especially privileged, and depend on mutual trust even though the burden of trust is balanced towards meeting the needs of the vulnerable patient (Entwistle & Quick, 2006). Contemporary health care environments are affected by issues such as medical error, iatrogenic injury, and medical fraud; moreover, media reports of litigation heighten health professional fears of disenfranchised consumers, which can further undermine trust (Entwistle & Quick, 2006). When navigating the healthcare system the patient and their families’ relationships of trust function on three levels (Entwistle & Quick, 2006). The first level is with voluntary trust, the second level is when patients believe themselves trapped without choice at a coercive level,
and, the third level is at a hegemonic level when trust is situated at an organisational level (Robb & Greenhalgh, 2006).

While the literature contains several discussions regarding the construct of trust, the work of Jennifer Job in bringing together relational and rational trust on the three levels will be presented in the following section as it provides a basis to understanding the construct of trust that is applicable to the decision-making process examined in this study.

Jennifer Job (2007) in her thesis ‘Ripples of Trust’ examined trust on three levels, namely a micro level which is the level of the family, a meso level which focuses on the community, and a macro level which focuses on institutions and governments. These three levels were utilised to examine how trust forms and erodes and its social and political determinants (p. 8). Job (2007) also examined trust in both a rational and relational way to propose an integrated view which is applicable to the context of organ donation decision-making in this current study.

An important finding from Jobs’ (2007) study was that trust is relational across institutions and that trust influences social interactions, a finding that has significance at the macro level for this study. The idea that trust is a ‘social bond’ and is multidimensional is consistent with the complex psychosocial phenomena being explored in this study. According to Job (2007), trust creates an expectation that others will do us no harm and have our best interests at heart, and leads to actions or endeavours of some kind’ (p.18). The sources of rational trust include ideas such as evidence, self-interest, predictability and logic whereas, relational trust
includes ideas such as emotion, faith, moral value, passion and belief with expectations built on these ideas that there will be no harm and best interests will be protected (Job, 2007, p.18).

A universal definition of trust has still not been achieved, and arguments about the basis of trust move between the idea that trust is formed in relationships and socialisation with others or learned through reason (Job, 2007). Moreover, the imbalance of power relationships between individuals and also between individuals and organisations can have trust implications (Job, 2007). The role of heuristics in helping to manage information that is required to build trust can have implications for the development of rational trust (Job, 2007). Job (2007) cites Valerie Braithwaite (1998), stating that ‘trust norms act as a basis for predicting trustworthiness in others, including institutions’ (p.27). In the environment of death and organ donation decision-making, the ability of decision-makers to grasp ideas and to trust their interpretations are clearly of significance as they come to their conclusions.

Job (2007) described the role of expectations, which are ideas based on trust and the author presents a definition for trust which combines rational and relational trust defined by Barber, as ‘social learned and social confirmed expectations that people have of each other, of the organisations and institutions in which they live, and the natural and moral social orders, that set the fundamental understandings of their lives’ (p. 28). This definition fits with the construct of trust in this study because the processes involved in family deceased organ donation decision-making require such complex relationships between individuals and organisations. This definition also fits the paradigm of decision-making before death in the context of society.
However, the complex emotions and other psychosocial factors suggest that the relational influences in the development of trust require further explication.

The idea of ethical connectedness and the impact of self-interest are important in the conceptualisation of trust. Job (2007) describes the basis of relational trust as ‘relational trust which is also called moralistic trust. This is based on the belief or faith in the goodness of others’ (Job, 2007, p. 31). Job goes on to argue that trust is multidimensional and that a wider view of trust is required to explain the complexity of the phenomena. This has implications for society and relationships, suggesting ‘trusting people to act in their self-interest is one thing and trusting them to live up to their obligations another. The former does not capture the bond of society, since the bond relies on trusting people not to exploit trust’ (Hollis (1998) cited in Job, 2007, p. 41).

Job (2007) described the basis of the formation of rational trust as contextually based and argued that it is an idea which differs from ideas of confidence, because confidence is a belief that first requires the formation of trust. These ideas have implications in the context of public attitudes towards organ donation decision-making where concepts of confidence in making decisions and ideas of trust are often used interchangeably and thus require clarification. It is impossible to extricate contexts of information, time and emotion from the family deceased organ donation decision-making process. Therefore, deceased donation decisions become reliant on the formation of trust not only in a relational way but also at a rational level. The formation of this trust may have occurred long before the donation decision, or may be altered by new information that is revealed at the time of the decision-making process. In the circumstances of
organ donation, it is suggested that decision-makers need to assure themselves at a rational level that everything possible is done for their family member and that their loved one is not harmed by the donation. In brain death circumstances this may not be readily apparent, thus requiring a relational aspect to help them develop trust. The level of trust then influences the decision-makers’ expectations surrounding the care of their family member’s deceased body, to ensure that the body and the identity are afforded dignity and respect in concordance with a peaceful death.

In practice the trust that the deceased places in the regulator by documenting an organ donation decision, is tested at this point, at a time when the hopes of the dying patients’ family move from the survival of the body to the survival of the memory and dignity of the person. Hope and deep hope may also figure at this point in time as minute by minute hope for the loved one’s family and the next step in living are forefront in the decision-makers conceptions. This may be followed by the possible vision of deep hope revealed as the hope of honouring the deceased, of giving life to others, or the hope of no further suffering, that may become the hopes of the family members to be able to entrust their family member’s body to good care.

The underpinning constructs that guided the inductive development of this theoretical framework are rooted in the literature, the community and participants narratives and the researchers’ clinical experience. Importantly, the theoretical framework that will be used to guide this entire study is framed within the case boundaries of the family decision-making process of deceased organ donation.
In summary, the preceding discussion has presented the three constructs of hope, deep hope and trust followed by a justification of why the Precaution Adoption Process Model, incorporating the three constructs as an eclectic theoretical framework will be appropriate to guide this study of the family decision-making process of deceased organ donation.

2.5 Conclusion

In Section One I presented an overall context to the study by situating the history of how death is determined and its philosophical meanings which have evolved over time. This area of health care continues to evolve; however, many of the early studies still contribute insights into this complex practice and have therefore been included. Their inclusion provides contextual clarity to understand approaches to deceased organ donation decision-making. I drew from literature that was particularly pertinent in the context of organ donation decision-making in the Australian environment because that is the contextual environment of this study. The care of the body at death and the use of deceased’ bodies and body parts were also traced over time in the context of Western society. The history of medicine and transplantation therapies was briefly outlined and the difficult ethical conundrums and perspectives which continue to challenge organ donation and transplantation practices were positioned to provide the reader with an overview of the basis of organ donation decision-making practices and their contexts in contemporary society.

In Section Two a focused approach was used to examine the research literature and identify the factors that contribute to family decisions regarding deceased organ donation, and the needs of families who make those decisions from three perspectives: namely, the organ
transplantation organisations, the health care professionals, and the families who are asked to donate. In Section Three, a discussion regarding the eclectic theoretical framework which will be used to guide this study was presented. Key studies that have contributed to the theoretical knowledge about deceased organ donation decision-making have been presented and the proposition that hope, deep hope and trust contribute to deceased organ donation decisions has been described. The following chapter will present the methodology utilised in this study.
Chapter 3: Methodology

3 Introduction

In Chapter 2, I presented a review of the literature underpinning this study. As previously mentioned, the purpose of the study is to identify the major factors that influence a family to agree or decline deceased organ donation during the process of decision-making. The aims of the study are three-fold: to identify the key stages and major influence’ in the decision-making process; to determine if hope, deep hope and trust play a role in the decision; and to explore families’ perception of their decision-making experience.

This chapter will provide a description and justification of the philosophical underpinnings of this research study including the paradigm, axiology and methodology. A description of the research design and methods used to maintain the trustworthiness and credibility of the study will be provided. The ethical considerations of the study including participant selection, recruitment and reciprocity will be presented. The positioning of the researcher and the applicability and transferability of the study findings will be described. Finally, the limitations of the study will be identified.

3.1 Justification of the research paradigm

Research, which can be defined as a ‘diligent, systematic inquiry or investigation to validate and refine existing knowledge and generate new knowledge’ (Burns & Grove, 2010, p. 2), is based on an evolving range of philosophical foundations. These are often derived from discipline-specific research questions that have contributed to theory development (Patton, 2002). Each paradigm presents a unique way of viewing the world, along with a range of
methodologies to support theory development (Denzin & Lincoln, 2005). In Chapter 2, a review of the quantitative and qualitative research findings provided insight into a range of factors that contribute to family deceased organ donation decisions. However, these findings do not fully account for the disparity between positive public attitudes towards organ donation expressed before death, and organ donation consent rates at death. In approaching this study, I seek to build on existing knowledge regarding family deceased organ donation decisions, and therefore require a paradigm that will allow the examination of human experiences involving a temporal event, located within real-world complexity.

Although quantitative methods are commonly used in health care settings and are a convenient strategy to capture data relating to a specific aspect of a phenomenon under investigation, they are unable to contextualise and explore authentic open-ended, in-depth responses to specific research problems. As a result, researchers are limited in their capacity to build knowledge regarding the varied contexts, interpretations and meanings that are fundamental to understanding the complex human experiences of relevance to this study. During the ‘paradigm wars’ (Yin, 2011, p. 287), it was argued that, in comparison with quantitative methods, qualitative research is ‘subjective, impressionistic, and anecdotal, rather than objective, systematic and generalizable’ (Wertz et al., 2011, p. 56). This view was countered by Yin (2011) who proposed that many quantitative studies are not objective in their design and purpose and that the results may be subjectively influenced both within subliminal and political contexts (p. 286). Therefore, Yin (2011) proposed that instead of debating which paradigm is the best for conducting research, researchers should select the best paradigm for the problem being investigated.
Qualitative research represents a holistic philosophical approach (Burns & Grove, 2010) that enables the researcher to explore the experience of the participant from within their own *world view* looking out from their experience, known as the *emic* perspective (Yin, 2011). Meanwhile, the researcher, who is outside the experience, must strive to look in and *see* the participant’s view, or the *etic* view (Yin, 2011). Importantly, the researcher must recognise and balance this *duality* of meanings when interpreting the available data (Yin, 2011) thereby enabling the researcher to gain an understanding of how the experience was perceived by the participant. Moreover, it is argued that the value of qualitative research is ‘not to reveal causal relationships, but rather to discover the nature of phenomena as humanly experienced’ (Minichiello, Aroni & Hays, 2008, p. 10). Therefore, by utilising interpretive research strategies, which provide specific methods for the researcher to reveal and create meaning from the world where the phenomenon of interest is situated, researchers become observers and interpreters of the natural world (Denzin & Lincoln, 2005, p. 3). In complex situations, where truth and meaning may be obscured by contextual influences, it is important to find a ‘basic set of beliefs’ or paradigm (Denzin & Lincoln, 2005, p. 183) that permits exploration of the truth being sought. Further, when planning a study, the researcher is obligated to demonstrate ‘moral discernment’ (Christians, 2005, p. 153) in selecting a paradigm that is philosophically appropriate to the problem and sensitive to the human experience (Denzin & Lincoln, 2005).

Constructivism is a paradigm that allows the researcher to capture the views of those whose experience is being examined. When using a constructivist approach, it is possible to acknowledge the differing *realities* experienced by the participants as constructed and co-constructed with the researcher, as relative interpretations of realities made visible by the
researcher (Denzin & Lincoln, 2005, p. 193). Constructivism is underpinned by the idea that studying humans and the social world is different from studying the physical world (Patton, 2002). Patton (2002) argues that the view of reality, seen by humans is in fact constructed from their perceptions and interpretations, which are founded within their personal language and cultural constructs (p. 96).

Questions about the basis of truth and the strategies and methods to reveal, interpret and define truth remain the focus of ongoing philosophical inquiry and debate (Smith & Hodkinson, 2005, p. 917). Patton (2002, p. 96) builds on the work of Shadish (1995b) and Neimeyer (1993) in presenting the constructivist argument that knowledge is not objective, but is a ‘construction’ of reality. This position rests well with the scope and complexity of the problem being investigated in this study, which will explore the many truths as understood by each individual involved in the decision-making experience. The scope of this inquiry is circumscribed by the ontological relativist proposition that forms the basis of constructivism, which proposes that ‘no world view is uniquely determined by empirical or sense data about the world’ (Patton, 2002, p. 97).

The constructivist paradigm contends that experiences and meanings are relative and co-constructed, and that social reality is not absolute (Yin, 2011). Methodological procedures that underpin the constructivist paradigm include a capacity for the researcher to use their interpretative skill as a tool to subjectively co-create understandings with the participants, using a hermeneutic/dialectical process to build an understanding of phenomena of interest (Guba & Lincoln, 2005). This epistemological stance provides opportunities to identify rich, credible
meaning derived from the authentic narrative of family members that have experienced these events. The trustworthiness of the data is enhanced because they are situated in the *real world* of the participant experience, a naturalistic environment, which contributes authenticity to the findings (Denzin & Lincoln, 2005). Further, the constructivist paradigm creates opportunities for the inductive development of substantive–formal theory when properly applied, and supports a methodology that is appropriate for use in interpretive case studies (Denzin & Lincoln, 2005, p. 24).

On this basis, a constructivist paradigm will be used to provide a philosophically robust framework to ‘reconstruct’ (Lincoln & Guba, 2005, p. 184) an understanding of families’ experiences of deceased organ donation decision-making, which will address the purpose and aims of the study. The people who made the deceased organ donation decision are best placed to accurately reveal the basis for their decision, its meanings and implications. The possibility that health professionals involved in caring for the deceased may have a different view regarding the factors that influenced family decisions is not relevant to the aims of this study. This is because the decision is made within the family and is based on the family’s interpretation of the events, and because the consequences of the decision affect the family. This position is supported by Patton (2002), who draws from Thomas’ (1928) theorem to argue that what people believe is real has consequences that are real (Patton, 2002, p. 96).

### 3.2 Axiology

The challenge facing the researcher seeking to ‘peel back’ the elements of novel events such as family deceased organ donation decision-making is to meet the ethical responsibility of
sensitively protecting and accurately representing the voices of the participants, while enabling the *truth* of rich, insightful, meaningful and credible information to be revealed. The ability of the researcher to give *voice* to the research participants is situated when ‘deciding who and what to quote, [and] involves decisions about whose voices will be heard’ (Patton, 2002, p. 495). Therefore, the researcher’s role in being alert to accurately representing and responding to the *truth* and perceptions of *truth* revealed by the participants and entrusted to the researcher, requires explication.

A strategic risk to the credibility and trustworthiness of qualitative research comes from the way in which the position of the researcher is viewed, as well as how the researcher manages questions of objectivity, subjectivity and neutrality when representing participants’ views (Patton, 2002). Patton (2002) suggests that an approach of ‘empathetic neutrality’ (p. 51) may be a better way for the researcher to commit to ‘understand the world as it unfolds, be true to complexities and multiple perspectives as they emerge, and be balanced in reporting both confirmatory and disconfirming evidence with regard to any conclusions offered’ (p. 51).

The decision to maintain participant confidentiality falls within complex interpretations and assumptions of power involved in collecting and interpreting data and communicating study findings, because the researcher is credited with authorship whereas participants remain anonymous (Wertz et al., 2011, p. 85). In most circumstances, ethics committees require study data and communications to be de-identified; however, these practices have implications for participants that may not wish to remain anonymous. To address these issues, it is important for
the researcher to identify, interpret and respond to these possibilities, to ensure that participants receive sufficient information when deciding to participate in a study.

The question of reciprocity and acknowledgement of participants will be a significant contextual element in this study. The participants may be emotionally vulnerable when asked to remember an experience that may have caused them distress. Further, the experience of retelling the story has the potential to generate anguish and exacerbate existing grief. Therefore, the experience of the interview and the information captured in the interview can be perceived as benefiting the researcher, but not the participant. The researcher is obligated to consider and address these aspects of the research relationship to ensure participants are under no misapprehension about how their contribution will be acknowledged and represented. It is also important that participants’ emotional investment in the study is acknowledged.

This topic area is ethically intricate and encompasses complex questions about death, bodily integrity, grief, relationships, the role of health care professionals and their engagement with families at the end of life. Further, it is a politically sensitive area as revealed in the dominant public narrative that organ donation is a virtuous act to rescue dying patients with organ failure. Therefore, it is possible that participants that have declined organ donation may be conflicted about their decision in the context of public approbation of those that decline deceased organ donation. Their decisions may have implications for the way in which their views are represented, particularly within the context of organisation power dynamics and the media, and some may believe that their voices are suppressed. There are significant funding implications attached to increasing organ donation performance in hospitals, and implications for the
accountability of governments that have publicly endorsed and funded organ donation programs. The background, knowledge, skill and position of the researcher will have implications for the trustworthiness, credibility and dependability of the findings.

The integrity of a study is enhanced when the researcher utilises strategies to ensure trustworthiness, credibility and accountability within the researcher–participant relationship, as well as in the analysis and findings. In this study, participants were asked to relate their experiences, which may have been deeply personal and emotionally challenging. The integrity and credibility of the study findings are dependent on the researcher being fair to the participants when representing the truth from the data that underpin the study. Patton (2002) emphasises that a unique characteristic of qualitative research is the ability of the researcher to empathetically learn about the participant’s world in a neutral but not detached way.

When conducting this study, I brought existing insights, knowledge and experience of the subject, context and phenomenon under investigation. The potential participants were informed of the purpose of the study, as well as my professional experience, which may have dissuaded some from participating. Others may have participated because they were motivated by the desire to gain a better understanding of the events surrounding their family member’s death. It was paramount that I recognised and addressed the risk to the study that my voice rather than the voice of the participants were presented.

Guba and Lincoln (2005) reflect on the evolving position of values embedded in interpretive paradigms, and discuss the role of spirituality (religion) as a legitimate inquiry
moving into the constructivist paradigm. In this study, it was important for me to recognise that the participants may have deeply held views and experiences that relate to their beliefs and spiritual senses. Therefore, I was open, respectful and accountable for insights that were shared with me when the participants described their experience of the death of their family member and when making decisions that may have had spiritual and religious significance to them.

Christians (2005) speaks of the need for researchers to ‘engage in the same moral space as the people they study’ (p. 155), and Lincoln and Denzin (2000) suggest that researchers’ findings should not be assessed for robust qualities, but instead for ‘their vitality and vigour in illuminating how we can create human flourishing’ (p. 155). While conducting this study, I sought to accomplish these goals.

3.3 Justification for the research design and methodology

The exploratory nature of this study, and the sensitivity and complexity involved for individuals and their families when making an organ donation decision, led to the conclusion that an exploratory case study design would be a suitable approach for this study. This exploratory case study was designed to examine the *case*, which is defined as the family *decision-making process of deceased organ donation*. Each participant’s experience was bound in time and context by the decision. The people best placed to provide an insight into the case were the decision-makers that were involved in making a deceased organ donation decision. Therefore, the study explored and interpreted the decision-makers’ experiences.

Case study design was chosen for this study because it supported the examination of *how* and *why* questions where it is desirable to explore, interpret and construct meaning that may have
been obscured by the complex nature of the phenomena under investigation (Yin, 2009). Yin (2009) defines case study as ‘an empirical inquiry about a contemporary phenomenon (i.e. a ‘case’), set within its real-world context—especially when the boundaries between phenomenon and context are not clearly evident’ (p. 4), which was a significant challenge that was addressed in this study.

3.3.1 Empirical materials

This is an exploratory study and therefore the empirical materials used to inform this study were collected from two sources. The first source of data comprised unstructured, in-depth open-ended recorded interviews conducted with family members that met the criteria for the study, and the second was the researcher’s journal and field notes.

Case study methodology utilises a theoretical approach that relies on interview data for analysis and interpretation (Yin, 2009). Minichiello, Aroni and Hays (2008) propose that in-depth qualitative interviews provide the researcher ‘access to the motives, meanings, actions and reactions of people in the context of their daily lives’ (p. 10) to provide authentic, credible and trustworthy data. Therefore, participants were encouraged to tell their own story of their decision experience, by using their own language to reveal the ‘dimensions, themes, and images/words people use to describe their feelings, thoughts and experiences’ (Patton, 2002, p. 354). This freedom of expression provided them with agency to communicate their views (Kamberelis & Dimitriadis, 2005).
In-depth open-ended interviews provide insight into human experiences in situations where it may be difficult for an outsider to understand the feelings and meanings involved, when the experience is hidden, or when elements of an experience may be masked to anyone other than the individual that experienced the event (Minichiello et al., 2008). Open-ended naturalistic interview approaches (Denzin & Lincoln, 2005) allow the researcher to explore and probe an event that cannot be predicted, is difficult to observe, and cannot be understood without detailed explanation by those who have experienced the phenomenon (Yin, 2011). The rich narrative that is derived from open-ended interviews is not constrained by the researcher’s knowledge, background or questions, thus allowing the participant to bring new knowledge, meanings and understandings to the phenomena under investigation.

The trustworthiness and credibility of this study depends on the authentic representation of the voices of those with deep knowledge of the experience. Therefore, it was important to recruit participants that could remember and communicate contextual detail about their experience, to ensure that their ‘actions can be understood in the context of the experiences and patterns of meaning that influence them’ (Liampittong, 2013, p. 390). It was crucial to obtain rich, thick narrative description from participants in order to construct a meaningful understanding of their experience (Denzin & Lincoln, 2005).

Chase (2005) posits that the relationship between the interviewer and the interviewee may be transformed during in-depth interviews. Chase (2005) suggests that the researcher–participant relationship becomes one of listener and narrator and the participant is able to guide and explain the context and meanings that inform the phenomenon of interest, which in this study was the
deceased organ donation decision. When discussing the possibilities of this relationship, Chase (2005) specifically emphasises the role of the researcher to invite the participant to move beyond generalisation to enter into the particular of the case by using the interviewer’s knowledge and skill for ‘listening to—for interpreting—the complexity and multiplicity within narrators’ voices’ (p. 663). The ability to locate and describe ‘the ambiguities and complexities’ within the participant’s story is greatly enhanced when using the in-depth interview process; however, this can only be achieved after a relationship of trust and rapport between the interviewer and participant is developed, to guide understanding (Fontana & Frey, p. 708). The ability to explore this level of experience is only available via open-ended in-depth interview techniques.

The second data source comprised a researchers’ journal and field notes, to record observations, and to employ reflexive and interpretive researcher skills (Yin, 2011). The researcher role was explicated in the researcher journal and field notes wherein was recorded rich contextual description of information about the location and conduct of the interview, the relationships between the people interviewed and the location of events, and the meaning ascribed to this kind of information. These data were collected and utilised in supporting my role as an instrument in the collection and interpretation of the participants’ ‘human experience’ (Patton, 2002) and in the inductive understanding of the case. Concerns about researcher objectivity, subjectivity, neutrality, empathy and bracketing are all situated within this aspect of data collection and analysis (Patton, 2002). My ability to respond to threats of credibility in the conduct of this research was positioned within my capacity to rigorously and intelligently attend to these questions. The researcher’s diary and field notes contributed to the trustworthiness and credibility of the study by allowing me to critically examine my position and understandings,
insights, questions, concerns and emerging ideas in the context of the interviews and cases, knowledge and experience (Yin, 2009).

The emerging ideas and reflections were documented, and a reflection was written following each interview in an effort to capture the immediacy of the event, the ideas that will be revealed, and the emotions and experiences that were described (Patton, 2002). The journal provides documentary evidence of the chronology of events, insights and epiphanies revealed in the conduct of the study. It also provided a ‘space’ to privately question the understandings and assumptions that I carry as the researcher. Patton (2002) highlights the importance of using reflection and ‘elaboration’ following an interview, within the time where the mind is engaged in the moment and captured by the event and this author argues that documenting these thoughts and experiences is essential to the data collection (p. 385).

3.4 Research procedure

3.4.1 Recruitment strategy

Following the development of the study methodology and design, an application was submitted for approval to conduct research involving human participants to the University of Canberra Committee for Ethics in Human Research. This milestone was achieved before recruitment commenced and is discussed further under ‘Ethical considerations’. It was important to follow the research design, which required a clear data management strategy prior to the recruitment of participants (Yin, 2009). A purposefully designed ‘Excel’ database and folder system was developed and maintained on a secure password-protected computer to record the
details of all data related to the conduct of the study, which also met the requirements for the ethical management of data (NHMRC, 2007).

The inclusion criteria for the study were limited to individuals that had experienced being a member of a family that had accepted or declined a request for organ donation on behalf of a deceased relative within the previous three years. This time frame was selected because it was reasonable to expect that most people would retain a fairly accurate memory of a significant event that had occurred within that period. It was also important that the experiences of participants were contemporary, to be relevant to the context and purpose of the study. These considerations were balanced with a necessity to ensure that the time frame was sufficiently generous to capture a sufficient sample to achieve the purpose and aims of the study. The sample was limited to English-speaking families recruited in Australia as it was not possible to include people who were unable to communicate in English. For the purpose of this study, family was defined as those that self-select as ‘family’ of the deceased, that are recognised as family in the naturalistic setting, and that were involved in the experience of the family making the organ donation decision on behalf of the deceased. Consistent with real-world experiences, family may include people without a legally recognised relationship. Depending on jurisdictional clinical practices, these people may or may not be involved in the formal decision-making action of providing written consent for organ donation.

Working with the University of Canberra media team and professional networks, a combination of public advertising through print media, television and radio interviews, websites and snowballing of information about the study was used to encourage families that had made an
organ donation decision within the past three years across Australia to participate in the study (Appendix 1). This strategy was augmented by the email distribution of the study invitation to professional organisations, general practitioners, religious bodies and social media messaging through Twitter, Facebook and other sites known to provide access to difficult-to-access groups (McLean & Campbell, 2003). In this study, family friends, family members and participants that were aware of other grieving families that met the study inclusion criteria contacted potential participants to make them aware of the study.

Early in the recruitment phase of the study it was noted that issues related to the use of terminology commonly used when discussing organ donation were causing community and researcher confusion in recruiting participants that met the selection criteria. The terms *organ* and *tissue* were used interchangeably in the public conversation, and difficulties arose when participants volunteered to participate in the study believing they had made a decision to agree or decline *organ* donation, when in fact they had declined *tissue* donation. Following this realisation, specific emphasis was placed during the recruitment screening interview to clarify with the potential participant exactly what the clinical experience had comprised when the family had been asked to donate. This ensured that recruitment was confined to people that had experienced the phenomenon under investigation. A total of 32 screening interviews led to nine families being included in the study. The theoretical framework was used to guide every step in the research process including the screening interviews.
3.4.2. Sampling strategies

A purposive, snowball sampling strategy was used to invite family members to participate in unstructured, open-ended in-depth naturalistic interviews. Purposive sampling enables the researcher to select information-rich cases that will provide the greatest insight into the problem for in-depth study (Patton, 2002). An effective method to optimise the case selection involves seeking out critical cases and locating information-rich key informants to support further ‘snowballing’ sampling (Patton, 2002). This strategy also assists researchers with difficulty in accessing a potentially vulnerable and hidden sample.

It is important in a case study design that the case has clearly defined boundaries to guide the collection and analysis of data (Yin, 2009). In defining the case in this study, it is recognised that there are multiple variables that will influence the context of a request for deceased organ donation. As previously mentioned, these may include the events leading to the death, the experience of the family as they become aware of the life-threatening situation, and the circumstances of hospitalisation, death, and discussion and decision about organ donation. Creating case boundaries is necessary to ensure that the data collected are appropriate to the research aims, and to support analysis. For the purpose of this study and as previously mentioned, the case was bounded by the deceased organ donation decision.

3.4.3 The setting and sample

The sample comprised nine families that had experienced the decision-making process of deceased organ donation for nine deceased individuals, from five of Australia’s eight states and territories. Five families agreed to, and four families declined deceased organ donation. The
decisions were made in critical care environments of ICU and ED and involved the donation process contexts of DCD and DBD. A total of 22 participants from metropolitan and regional locations across Australia were recruited and interviewed in 17 interviews (Table 3.1). Fourteen interviews were conducted face to face, and three by telephone. Of the 17 interviews, 12 were conducted with individual participants, and five with two or three participants.

Participants that came from three generations of the same family were interviewed separately regarding the deceased organ donation decision that was arrived at by their family. In another decision, two participants were first interviewed separately and then jointly with other family members. In seven family decisions, one or both parents of the deceased were interviewed. Six mothers and two spouses of deceased individuals participated in interviews. Siblings and other close family members were also represented in the sample (see Table 3.1, p.165).
Table 3.1

Seventeen interviews conducted with 22 participants from nine families

<table>
<thead>
<tr>
<th>Family</th>
<th>Participants relationship to the deceased</th>
<th>Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Husband</td>
<td>Interviewed alone</td>
</tr>
<tr>
<td>2</td>
<td>Wife&lt;br&gt;Son&lt;br&gt;Son&lt;br&gt;Mother in law&lt;br&gt;Father in law</td>
<td>Interviewed alone&lt;br&gt;Interviewed alone&lt;br&gt;Interviewed alone&lt;br&gt;Interviewed alone&lt;br&gt;Interviewed alone</td>
</tr>
<tr>
<td>3</td>
<td>Sister&lt;br&gt;Father</td>
<td>Interviewed alone</td>
</tr>
<tr>
<td>4</td>
<td>Brother&lt;br&gt;Sister&lt;br&gt;Sister</td>
<td>Interviewed together&lt;br&gt;Brother also interviewed alone</td>
</tr>
<tr>
<td>5</td>
<td>Mother&lt;br&gt;Father</td>
<td>Interviewed together</td>
</tr>
<tr>
<td>6</td>
<td>Mother</td>
<td>Interviewed alone</td>
</tr>
<tr>
<td>7</td>
<td>Mother&lt;br&gt;Sister&lt;br&gt;Sister</td>
<td>Interviewed together</td>
</tr>
<tr>
<td>8</td>
<td>Mother&lt;br&gt;Sister</td>
<td>Interviewed together&lt;br&gt;Mother also interviewed alone</td>
</tr>
<tr>
<td>9</td>
<td>Mother&lt;br&gt;Father&lt;br&gt;Aunt</td>
<td>Interviewed together</td>
</tr>
</tbody>
</table>

3.4.4 Instrumentation

This study used an unstructured approach to interviewing participants about their experiences of deceased organ donation decision-making. Minichiello et al. (2008, p.88) argue that the unstructured recursive model of interviewing is particularly suited to unique situations
where the researcher–researched interaction guides the research process. This model is described as a conversational interaction that relies on two levels of communication and involves the interviewer in listening, interpreting and directing the research through conversation with the participants (Minichiello et al., 2008). An interview guide was developed for use as a prompt and checking tool to help focus on the problem (Patton, 2002). The interview guide was limited to open-ended questions to enable a recursive pattern of conversation (Minichiello et al., 2008) to develop between the interviewer and the participants. The questions were drawn from three sources: the literature, anecdotal evidence and the researcher’s experience. The questions were designed to be exploratory within the confines of the case boundaries.

The initial interview guide comprised 10 questions chosen to initiate and encourage discussion regarding the decision experience. Patton (2002) describes this as the ‘general interview guide approach’ (p. 342). The questions were designed for use as prompts and related to the events known to occur in the hospital for families involved in deceased organ donation decision-making. These events were not chronological and the questions were not designed to be presented in a set order as that would restrict the nature of the interview (Patton, 2002).

The opening question was Would you like to please tell me about (name of person who died)? The question was asked to open the interview and gently direct the conversation towards the topic; simultaneously allowing time to respect the meaning of the deceased in the lives of the family. By opening the interview in this way, I was able to build rapport with the family. It is recognised that opportunities to talk about the deceased are valued by grieving family members and may also play a therapeutic role in their experience of bereavement (Holtkamp, 2002).
Further, participants’ responses enabled me to enhance my understanding of the relationship between participants and the deceased family member and the context of the death.

The question that followed was *Could you please tell me about what happened?* This question was framed to build on theory of the family decision-making process of deceased organ donation and to be consistent in design with a seminal study conducted by Sque and Payne (1996), in which families that had made deceased organ donation decisions were invited ‘to tell the story of their experiences’ (p. 1360). The interview guide was modified following the pilot interview when it became clear that the participant required little prompting in the interview to address the research question. It was found that the participant provided an extensive account of the decision-making experience in an unstructured manner with minimal prompting or probing. Patton (2002) asserts that specific questions are not appropriate in conversational interviews and emphasises how the context determines the emergent narrative. Following the pilot interview, the interview guide was refined to the seven questions presented in Table 3.2, which guided all subsequent interviews.

*Table 3.2 Interview Guide*

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Would you like to please tell me about (name of person who died)?</td>
</tr>
<tr>
<td>2</td>
<td>Could you please tell me about what happened?</td>
</tr>
<tr>
<td>3</td>
<td>Were you able to be with … ?</td>
</tr>
<tr>
<td>4</td>
<td>Can we now please talk a little bit about organ donation, for example, when was it first mentioned?</td>
</tr>
<tr>
<td>5</td>
<td>How do you feel overall about organ donation?</td>
</tr>
<tr>
<td>6</td>
<td>Is there anything you would like to add?</td>
</tr>
</tbody>
</table>
3.4.5. Pilot study

A pilot study was conducted to test the study research procedures prior to the major data collection. The benefits that may be derived by conducting a pilot study include a capacity to test the field protocol and interview questions to ensure that the purpose and aims of the study are being addressed (Yin, 2009). A pilot study also allows the researcher to ensure that the recruitment and sampling strategy meet the requirements of the study and the ethical obligations of the researcher to the participants (Yin, 2009). Further, it enables the researcher to examine the researcher–participant interaction to ensure that requirements and expectations surrounding reciprocity and reflexivity are appropriately addressed.

Following approval from the institutional ethics committee (Appendix 2), recruitment to the pilot study commenced in September 2011. A potential participant from the researcher’s local area agreed to participate, having previously made a decision to decline organ donation on behalf of a deceased family member. The potential participant met the inclusion criteria for the study, except for the time of the death, which was earlier than the prescribed three-year period. However, the latter criterion was considered less important in the context of a pilot study, and the proximity of this participant to the researcher was beneficial for two reasons. First, the ethical sensitivities that this study presented suggested the interview protocol and fieldwork protocol should be properly tested in an environment where the risk of harm to the participant and the researcher could be minimised. Second, it would enable familiarisation and testing of the recording equipment and the interview guide in the field.
The pilot study procedure involved first testing with the researcher’s supervisors the planned unstructured interview and the interview guide that was to be used for prompting. The recording equipment used in the study was also tested at this time, and the discussion about the study including the written information and the informed consent form was trialled with supervisors. This process helped to ensure that the research procedure was coherent and appropriate to the study before conducting the pilot interview.

During a telephone discussion with the participant, an interview time was arranged. The participant had indicated in the discussion that he had read the written information and the informed consent form for the study, and was willing to participate in a recorded interview at his home. Upon arrival at the participant’s home I followed the pilot study data collection procedure. First, I sought to develop a rapport with the participant, and commenced the interview process by reviewing the information about the study and the informed consent form with the participant. I explained that the interview could be stopped at any time and that he could also withdraw from the study at any time without repercussions. I expressed my thanks that he had volunteered to participate and provided contact details for 24-hour bereavement support. I asked if he had any questions. The participant was satisfied and signed the informed consent form. A copy of the signed consent form and information sheet was retained by the participant and I kept the signed consent form for the study records. Recording of the interview commenced after the participant indicated he was ready, with the question, *Would you like to please tell me about (name of the person who died)*? Followed by, *Could you please tell me about what happened*?
The interview guide was used once during the interview to help focus the interview on the phenomenon under investigation. It was used again at the conclusion of the interview to check that the questions included in the guide had been answered, which were noted as complete. The interview was concluded and I documented field notes and moved the conversation to more general topics to ‘lighten’ the conversation and to check that the participant was ‘alright’ before thanking him and leaving his home. Following the interview, I documented my reflection regarding the interview and its findings in my researcher’s journal. I searched for evidence of subjectivity on my behalf when conducting the interview. I also documented clarifying comments regarding the interview. I checked the audio recording for sound quality and completeness and I then transcribed the interview, checking and rechecking the recording for accuracy and meaning, and discussed the experience of the interview and the initial findings with my supervisors. The following day I telephoned the participant as previously arranged, to check that he was alright and to clarify any questions that had arisen from the interview data. The participant indicated that he was satisfied with my interpretation and comfortable with the interview experience.

3.4.6 Data collection procedure

Data collection commenced in September 2011 and concluded in September 2012. Once potential participants had undergone the recruitment screening interview and had been assessed as having met the inclusion criteria, they were provided with a letter of introduction (Appendix 3), a participant information sheet (Appendix 4), and the informed consent form (Appendix 5) either by email or surface mail. The potential participants were also contacted as previously arranged to ensure they had received the study information and the consent documentation, and
to invite them to participate in the study. The risks associated with participating in the study were explained, and they were invited to ask questions about the study. Interviews were scheduled and conducted at a time and location of the participants’ choice within Australia. The participants interviewed by telephone either faxed or emailed their signed consent forms back to the researcher or sent them by post. A researcher’s journal was maintained, and a fieldwork guideline (Patton, 2002, p. 331) designed to guide a safe and accountable approach to conducting the interviews. Most participants were interviewed in their homes and included other family members at their discretion.

Fourteen of the 17 recorded interviews were conducted face-to-face at a site chosen by the participants. Nine face-to-face interviews were conducted with a single participant, and five were conducted face-to-face with two or three family members. Three interviews were conducted by telephone at the request of the participants. The recorded interviews lasted between 30 minutes to four hours, averaging around 2 hours. At each interview, I introduced myself, thanked the participants, and reconfirmed their consent to the interview, which included ensuring I had the participant’s agreement to record the interview and to take notes. I checked the consent documentation and asked if the participant had any questions. The signed consent documentation was retained for the study records by the researcher, and a copy of the information sheet and signed consent form were provided to the participant for their personal files. I sought to establish a rapport with participants before the interview commenced, mindful of their vulnerability and the sensitivity of the subject. I explained how I would conduct the interview and checked with participants regarding how much time they had available. Before the interviews commenced,
participants were shown the interview guide and were informed that the interview could be stopped at any time if they became distressed by the experience or for any other reason.

Prior to commencing the interviews it was explained to participants that they would be asked a question about their deceased family member followed by a question regarding their experience of the deceased organ donation decision-making process. The interviews were sometimes stopped and then restarted when participants were crying or were required to attend to other needs such as answering a telephone or responding to a child. The experiences described in the interviews were interpreted through the participants’ ‘lens’ of bereavement. Although the interviews were unstructured as mentioned previously, the interview guide was checked at the conclusion of each interview to ensure the case data were complete. In all but two interviews, there was no need for prompting or questions as participants had provided a comprehensive narrative that was inclusive of the interview guide. Participants were provided with an opportunity to ask questions and seek answers to any issues that the interview may have raised with them at the time of the interview, and were invited to contact the researcher following the interview if necessary. The telephone contact details of support services and the researcher were provided to the participants prior to and mentioned again at the conclusion of the interview.

Following each interview, a short period was allowed to elapse to enable the conversation to move away from the emotionally challenging content of the interview to more mundane conversation. I used this time to verify that the participant had contact numbers for support services, to check that the participants were alright, and to thank them for their time. I explained that with their permission, I would telephone them several days later. The follow-up telephone
call was used to check on the wellbeing of the participant, to invite feedback or suggestions, and to ask any clarifying questions regarding my understanding and interpretation of their interview. Additional observational data and analysis were documented in field notes recorded at the time of the interview. Once I had left the site of the interview, I wrote field notes about the interview, and reflections in the researcher’s journal following the case protocol procedures (Yin, 2009).

3.5 Justification of the data analysis technique

Thematic analysis, an inductive approach, was utilised in this study because it was well suited to the exploratory, constructivist methodology employed. Thematic analysis is an analytical process that requires the researcher to systematically and rigorously examine narrative searching for consistent patterns, categories and themes (Minichiello, Aroni & Hays, 2008), as well as unexpected and emergent meanings (Liamputtong, 2013). Further, it relies on contextual information and care in ensuring the participant’s perspective is maintained (Silverman, 2011). For these reasons it was utilised to analyse the 17 in-depth interviews and a more detailed justification for using the thematic analysis technique will be presented in Chapter 4.

The theoretical framework was developed inductively from its initial roots in the literature, community narrative and researchers experience. It was used to analyse interviews and test the researchers understanding of the complex events, unexpected emotions, decisions and their implications described by the participants. The theoretical framework proved effective in providing a logical structure relevant to the problem to build an understanding of the complex information presented. Throughout the research process the theoretical framework was used to guide the inquiry, whilst at the same time I checked and tested its effectiveness by searching for
gaps in my understanding of the participants’ narrative in collaboration with the participants, the literature, subject experts and research supervisors. This process was consistent with the constructivist paradigm chosen to guide this study.

Following each interview, the recordings were replayed to check for sound quality and accuracy. The interview recordings were also checked for clarity and meaning against the interview guide, the researchers’ understanding of the events and the theoretical framework. The chronology of the decision and the role of family members in the decision-making process and other pertinent information were reviewed for clarity; the details were de-identified and recorded in the case study database. I then reflected on the information and my understanding of what I had been told, checking for gaps. I utilised my professional knowledge to interpret the clinical context of the participants’ decision-making experience, and critically reviewed my interaction with the participants for signs of subjectivity. Fieldwork notes and observations were recorded and the researcher’s journal was updated immediately following each interview. A de-identified electronic case record was kept for each participant. In some instances, participants generously contacted me on several occasions to provide additional information and material such as media recordings, print articles and books that they believed would assist me in forming a better understanding of their decision experience. I carefully reviewed and considered these additional sources of information that were provided to me firstly because they were viewed as important by the participants, secondly because they enhanced my understanding of the participants’ view.

A de-identification code book with pseudonyms and a family tree describing each family was kept to ensure contextual clarity in the analysis. I transcribed the first six recorded
interviews verbatim and utilised professional transcription services for the 11 subsequent interviews. Data collection ceased in September 2012 when it was decided that there were sufficient recurring themes within the data to suggest saturation had been achieved.

3.6 Ethical considerations

The University of Canberra Committee for Ethics in Human Research provided approval to conduct the study from 8 July 2011 until 1 January 2014 (Project number 11-60, see Appendix 2). The risks and benefits for individuals that chose to participate in this study required careful explication prior to the study. As a higher degree research student, it was essential that I worked closely with my research supervisors to ensure that the right to informed consent and privacy of participants, and potential risks such as physical and emotional harm (Fontana & Frey, 2005) were identified, disclosed and appropriately mitigated. The research supervisors provided oversight to ensure the study design was appropriate for the methodology, and that the fieldwork protocol appropriately recognised the involvement of the participants. Further, they assured that I had the research skills to conduct the study.

This study was designed to engage with people that are potentially emotionally vulnerable following the death of a family member. By interviewing participants about their experience of the events including and surrounding the death, it was expected that they would revisit the emotions they experienced at the death, which may have caused them further distress. However, in my professional experience as a nurse, I have observed that often family members that experience bereavement are grateful when someone listens, and hears them tell their story about the death of their family member. For some, the experience may feel cathartic. A comment
I have heard from bereaved families in my previous experience is that they would like more opportunities to talk about their experience, and about their deceased family member but find people either do not want to listen, avoid them or tell them to get over it, and move on. Further, there are limited opportunities for bereaved individuals to discuss their hospital experiences with health professionals. Thus, the possible risk of harm to grieving individuals that had experienced the death of a relative was balanced both against the benefits of providing bereaved families a chance to express their views, and the long-term benefits that this study may bring.

Importantly, there were no inducements or material benefits to be gained for individuals that chose to participate in the study, and the researcher position was clearly and truthfully represented to the participants at the time of recruitment. The participants were informed that the findings from this study will lead to recommendations regarding strategies to help increase the number of families that agree to organ donation at a clinical, organisation and policy level.

The study purpose and aims, and my role as the researcher, are not value neutral (Smith, 2005), and were made explicit. I am aware from my clinical experience that an important aspect of protecting participants includes being able to assure them that the research is independent of the organisations involved in their experience. Therefore, the research protocol ensured that the purpose of the study and my previous experience as an organ donor coordinator nurse was revealed to potential participants during the recruitment phase of the study. This was to provide potential participants with sufficient information to assess the researcher’s knowledge of the subject area, which is part of ensuring participants are given sufficient truthful information to make an informed decision to participate in the study (Fontana & Frey, 2005). Therefore, as
previously discussed under the heading, ‘Data collection procedure’, information about the study was distributed to potential participants using an information sheet (Appendix 4) and informed consent was obtained from each participant prior to interview (Appendix 5).

During the recruitment screening interview I discussed the study with potential participants and explained that they could withdraw from the study at any time without prejudice. I provided participants with the contact details for bereavement support services, and university contact details in case they wished to make a complaint, or provide feedback regarding the study, before they were asked to sign the informed consent form. The study protocol was designed to enable participants to have open-ended interviews in naturalistic locations at a time, and with people of their choice. Following the study protocol, and in meeting the requirements of the ethics committee, all interview data were promptly de-identified and pseudonyms were used. The data were secured in a password-protected computer. An identification code book was also secured in a separate password-protected computer. All files and data were secured in a locked cabinet and in a password-protected computer for a minimum of five years to meet the requirements of university policy, and the National Statement on Ethical Conduct in Research Involving Humans (2007).

This chapter has used value-neutral language that does not make claims or assertions about the level of emotion, trauma and tragedy that may have been experienced by family members that participated in this study. Further, I have been careful not to make claims about the relationships between individuals involved in the study or the range and depth of feelings related
to the decision, and experienced by family members and significant others that may be aware of
the decision experience and the study.

### 3.7 Credibility and trustworthiness

A credible qualitative study will display a *fit* between the researcher’s interpretation and
participant view (Liampittong, 2013). Judgments regarding the quality and credibility of
constructivist studies require criteria that can demonstrate authenticity, trustworthiness and
dependability (Patton, 2002). A quality constructivist study will recognise and account for
subjectivity and will use triangulation to capture multiple perspectives (Patton, 2005). Other
strategies that enhance the credibility of qualitative studies include the use of researcher
reflexivity and evidence of analytic transferability to other populations and contexts
(Liamputtong, 2013). I will now describe how these strategies were used to enhance the integrity
and credibility of this study and its findings.

Six steps were followed to ensure rigour in the conduct of this study. Each step addressed
requirements for authenticity, trustworthiness and dependability to a greater or lesser degree. The
first step involved selecting a methodology and protocol that was appropriate to the research
question. As mentioned above, it was important to select an appropriate methodology to meet the
aims of the study in order for the study to be deemed credible (Liamputtong, 2013). The second
step for ensuring the credibility of this study involved the consistent application of the same
study protocol throughout the entire study. This strategy strengthened the dependability of the
study first by providing a transparent audit trail (Yin, 2009); and second, by ensuring consistent
procedures and practices for data collection, management and analysis.
The third step involved the collection of credible data. In this study, this was addressed in the purposive recruitment of participants with ‘knowledge and unique characteristics’ (Liamputtong, 2013, p. 25) that were able to provide an authentic representation of the phenomenon and a rich description of their experience. To be credible, the study needed thick authentic description from credible and trustworthy sources (Liamputtong, 2013). Additionally, the participants engaged in open-ended unstructured interviews in a naturalistic setting that supported the development of trust between the participants and researcher. This rapport enhanced the quality of the participant’s thick narrative. Further, the truthfulness of the narratives was supported because the information provided, through telephone conversations and emails during the recruitment phase of the study and following the interview with participants when follow-up conversations and emails occurred, remained consistent across an extended period, which is another measure of credibility (Liamputtong, 2013).

The fourth step followed to maintain credibility in this study involved the management and analysis of the data. As previously mentioned every interview was transcribed verbatim and then checked against the interview guide to confirm that the data collected were complete and consistent with the participant’s view. Further, the study protocol required me to examine the completeness of the data following each interview and to check my understanding of the interview using the field notes, researcher journal, recording, transcript and any additional communications with the participants, guided by the theoretical framework. This strategy enabled me to address questions regarding the authenticity and trustworthiness of the data, their interpretation and dependability. The data were also assessed to check that they would address the aims of the study. I worked closely with my supervisors throughout the recruitment,
interview, transcription and analytic phases to use their independent positions to check for consistency and meaning in the interpretation of the data, to limit subjectivity and to enhance the dependability of the data analysis, its management, and the logic linking the data (Yin, 2009). In addition, supervision meetings were used to discuss the progress of the study and to address potential confounders to credibility such as recruitment of the sample and questions of interpretation and the use and effectiveness of the theoretical framework.

Confirmability was addressed via several strategies including member checking and triangulation. Member checking (Yin, 2011) was used at various points throughout the study. The first member check occurred during the in-depth interviews when I used clarifying questions to check my understanding. The second member check occurred at the conclusion of the interviews when I checked the chronology and my interpretation of the events with the participants. This information was recorded in field notes and in my researcher’s journal. The third member check occurred when the interview transcriptions were checked against the recorded interviews for meaning and context. If questions arose, the participants were contacted and asked to clarify and check that the interpretation was correct. A fourth check was when the analysis and findings of the interview data were checked with available participants in discussions about the progress of the study, and in presentations during which available participants were invited to attend conference presentations and to provide feedback to the researcher and supervisors. Participant feedback confirmed the accuracy of the representation and analysis of their interview data. These processes all enhanced the credibility of the study by ensuring that the data and their interpretation were confirmable.
The fifth step to ensure the credibility of this study required me to demonstrate evidence that my interpretation of the narrative accurately reflected the participants’ themes and experiences. This was achieved by the use of data triangulation (Liampittong, 2013) to ‘capture and report multiple perspectives, rather than report a singular truth’ (Patton, 2002, p. 546). This study explored participants’ experiences in interviews with individuals or with small groups of participants, and therefore provided multiple perspectives of the decision. This process enabled the particularity of each decision experience to be represented authentically, while contributing multiple perspectives. Professional knowledge was utilised to interpret the participant’s data, and the literature was utilised to triangulate the data during analysis. The use of reflexivity (Patton, 2002) was addressed within this fifth step. Importantly, data checking with supervisors, participants, consumers, professional experts in the field and the literature provided additional means to test the goodness of fit of the data and the conclusions that were drawn. This process contributed to the credibility and trustworthiness of the findings. I closely scrutinised the data seeking to identify new and unexpected patterns, and to ensure that emerging ideas were identified (Patton, 2002, p. 56). It is important to emphasise that although triangulation is useful for strengthening the credibility of a study, it has potential pitfalls. Conflicting information or unique findings may emerge using this process, and it is important that these findings should be addressed (Liamputtong, 2013). Further, a limitation when triangulating data sources is that the data obtained may simply add information rather than clarifying or consolidating a position.

The sixth step involved addressing the requirement for transferability to demonstrate that the study theory is applicable to other contexts (Liamputtong, 2013). The transferability of this study is discussed in Chapter 5 where it is argued that new theory from this study may be
transferable to other contexts of health care involving complex family decision-making. Transferability will be discussed further in this chapter.

### 3.7.1 Researcher reflexivity

The quality of a constructivist study is also judged by its ability to address questions of reflexivity, praxis and particularity; further it should exhibit evidence of *Verstehen* or ‘deeper understanding’ (Patton, 2002, p. 544) in its conduct, analysis, findings and conclusions. The use of researcher reflexivity was recognised as integral to the credibility and trustworthiness of the study. Researcher reflexivity and praxis require the researcher to recognise the personal role they play in the study, because of their personal subjective background, knowledge, understanding and interpretations that influence their behaviour, interpretations and interactions in the world around them (Patton, 2002). Researcher reflexivity was used in positioning my critical care and organ donation nursing knowledge and experience when conducting and analysing interviews. Although Yin (2009) proposes the quality of the case study is enhanced if the researcher is experienced in the phenomena under investigation, the researcher as an instrument is limited by her *etic* (outsider) position and has incomplete knowledge of the study phenomena. From the inception of the study, a researcher journal and field notes were used to capture important interview detail, document insights, questions, revelations and reflections.

The potential difficulty in conducting the interviews came from my clinical experience in this area of practice, which led to a possibility of assumed interpretations of the interview data and the risk of researcher bias based on my knowledge and subjective experience. There was also the possibility of therapeutic engagement with the participants in the conduct of the interviews,
which could confuse the relationship between the participants and researcher and distract them from the aims and purpose of the study during the interviews and when analysing the data. As mentioned previously, this needed to be balanced against the requirement for empathetic neutrality, mindfulness (Patton, 2002, p. 40) and sensitivity when conducting and interpreting the interviews.

Therefore, I utilised a carefully constructed mental framework (Yin, 2011, p. 139) in the approach to each interview and its interpretation. Yin (2011) suggests that this framework helps the researcher focus on the original questions while being open to new and unexpected insights. The mental framework used in this exploratory case study is delineated by the requirement that I should be sufficiently knowledgeable about the topic to understand ‘what is being explored and why, and what the investigator hopes to learn from the exploration’ (Yin, 2010, p. 3). Yin (2010) advises that although the researcher may wish to reveal all structures that inform the analysis, the framework should be held privately to enable the researcher to maintain a neutral approach and limit perceptions of ‘reactivity bias’ (p. 4) in approaching and analysing the interviews. This framework enabled me to consistently check the data and critically analyse where the data triangulated, converged (Mills et al., 2010) or crystallised to check for gaps and unexpected insights. Yin (2010) advises that the researchers’ mental framework should be flexible enough to recognise and respond to evolving and developing patterns and knowledge, and this was achieved.

Further, the credibility of the study was enhanced because participants were able to choose the location of their interview, which addressed the possible perception of a researcher–
participant power imbalance when an interview is conducted in an unfamiliar setting (Bishop, 2005). This was important: first, because the researcher wished to ensure that the participants felt secure in their relationship with the researcher and comfortable in the context of the interview; and second, to ensure the participants were within a supported environment to empower them to give a complete account of their experience. The third reason that the researcher sought to interview in a naturalistic environment was to enable the researcher to gain insight into the participant’s ‘world’ and acquire a greater understanding of their world view. This strategy was used to strengthen the credibility and authenticity of the data collection and interpretive process (Liamputtong, 2013).

3.8 Transferability

Patton (2002) discusses the varied interpretations that qualitative researchers such as Cronbach (1975), Stake (1978) and Guba (1978) have used to expound on the idea of generalisability or transferability when describing qualitative research. There is an argument that it is difficult to generalise in social science and any effort to generalise requires careful attention to the specific context and particularities of the case (Patton, 2002). Important ideas used in assessing the merit of a study, including the idea that when a researcher identifies patterns and similarities, and intuitively or naturally generalises, led Lincoln and Guba in 1985 to propose that transferability and fittingness were concepts that better expressed qualitative ideas of generalisation (Patton, 2002, p. 584). Patton (2002) described how Cronbach and colleagues (1980) argued that extrapolation is a better term to explain concepts of generalisability and transferability for qualitative studies. Patton defined extrapolation as ‘modest speculations on the likely applicability of findings to other situations under other similar, but not identical,
conditions’ (Patton, 2002, p. 584). This definition is appropriate to this study and its findings because it is clear that there are particularities in each circumstance of decision-making that cannot be replicated. However, it is likely that this study and its findings are applicable to other settings where similar findings may be possible, and it is probable that the findings from this study may resonate with other individuals that have made deceased organ donation decisions.

3.8.1 Methodological limitations

Although the study comprised a small sample size, which could be argued is a methodological limitation, the rich narrative data and thick description provided by the participants provided valuable insight into the meaning and experiences involved for the families, and became a strength. Each singular case in this study becomes critical or paradigmatic because it is effectively the only authentic representation of the experience. Each decision carries important information that will contribute to findings that are generalisable to theory, because ‘it is believed that understanding them will lead to better understanding, and perhaps theorizing, about a still larger collection of cases’ (Stake, 2005, p. 446).

First, it is possible the recruitment was hampered by community confusion in understandings of the organ donation terminology used in the study invitation. The words organ, tissue and body (body parts) were noted to be used interchangeably and with interchangeable meanings by some who responded to the study invitation. Misunderstanding was noted throughout the recruitment phase in the communications between the researcher and interested individuals when it became evident that assumptions and understandings held by the community about the purpose of a deceased organ donation decision could be interpreted as being either for
use in human transplantation, research or both. Confusion regarding the terminology commonly used by health care professionals when communicating about organ donation was evidenced throughout the study not only in both the responses received in the recruitment phase, but also in the interview data.

Second, it is possible that some families that qualified for the study may have been uncertain about their eligibility and not volunteered. This concern arose because I noted that in five of the nine decisions represented in this study, participants were encouraged to contact me by their friends and extended family, having previously assumed that they did not meet the study criteria. Further, individuals were encouraged not to participate if they believed their participation would cause additional distress to them or their family, a factor that further limited participation.

3.9 Conclusion

This chapter has provided a justification and description of the philosophical and conceptual methodology and axiology utilised in this study. The chapter commenced with a justification of the use of the constructivist paradigm to ‘reconstruct’ an understanding of the family experience of making an organ donation decision. The decision to use a case study methodology was justified and an explanation and description of the methods used was presented and discussed. The axiology of the study and the researcher position were presented. Justification for the use of a purposive sampling strategy was provided, and the sample was described. The audit trail utilised for data collection, analysis and management was delineated. Strategies to ensure authenticity, trustworthiness and credibility in the study method and findings were
justified. The ethical considerations of the study including participant selection, recruitment and reciprocity were identified. The applicability and generalisability of the findings were discussed, and finally, the methodological limitations were presented. In Chapter 4, I will present the justification for the data analysis technique and the findings from this study.
Chapter 4: Analysis and Findings

4 Introduction

This chapter presents the case analysis and findings from interviews with participants that experienced the family decision-making process of deceased organ donation. As previously mentioned, the purpose of this study was to identify the major factors that influence a family to agree or decline deceased organ donation during the process of decision-making. The aims of the study were three-fold: to identify the key stages and the major influencers’ in the decision-making process; to determine if hope, deep hope and trust played a role in the decision, and to explore families’ perceptions of their decision-making experience.

This chapter is structured with a focus on providing a trustworthy representation and analysis of the experiences described by the participants in this study. I have sought to ensure that the authentic voice of the participants and the truthfulness of their decisions are represented.

The chapter first presents the justification for the data analysis technique used to examine and interpret the qualitative exploratory case study data. This is followed by the demographic characteristics of the 22 participants. The chapter then presents the findings from the in-depth unstructured interviews during which the family members described their deceased organ donation decision-making experiences. These are presented within three major themes—*In the fog drowning, It’s all up to Mum* and *Harvesting humanity*—and their six sub-themes: *This is how it happens, Stop all the clocks, Well you never give up hope, Trust protected, Sack of body parts* and *Sacrifice of peace at death.*
4.1 Justification for the data analysis technique

As previously discussed, this case study was designed using an exploratory constructivist qualitative methodology bound by the case of the family decision-making process of deceased organ donation. A case study design and protocol (Yin, 2009) (see Chapter 3) guided data collection, management and analysis to provide a clear trail for credible and trustworthy results. An interview guide, audio-recordings, interview transcripts, researcher field notes and researcher journal provided contextual, reflective and ethical coherence to the analytic process. The theoretical framework, my professional knowledge and literature sources were used to position and triangulate (Yin, 2009) the emerging ideas about the human experience described by the participants.

This iterative analytic process enabled me to focus on addressing the study purpose and aims, and enabled early identification of points in the data collection where the protocol or analytic strategy required modification, as recommended for case study methods (Yin, 2009). Creswell (2011) describes this inductive process as ‘emergent design’ (p. 176). Each death was approached separately and each interview was analysed and interpreted individually following the case study protocol (Yin, 2009). The events and experiences described by the participants were analysed chronologically; which was an important contextual element of this study and linked to the theoretical analysis.

The analysis and interpretation was an iterative process, guided by the theoretical framework that commenced with the purposeful recruitment of cases and the pilot study, and continued until analysis and interpretation were complete (Yin, 2009). Stake (2005) suggests it is
not within the constraints of practicality to understand all of the case because of the large quantity of data generated via this research method, and he therefore, emphasises the careful selection of significant thematic material for analysis.

A de-identification code book with participants’ pseudonyms and a family tree describing each decision was kept to ensure contextual clarity in the analysis. Detail about the deceased such as their age, critical injury, donation pathway and environment where the decision took place was collected but specifically de-identified in the reporting of this study to protect the identity of the highly identifiable participants. I transcribed the first 6 of the 17 interviews verbatim. The 11 subsequent interviews were professionally transcribed and then checked via the following process: once each transcript was completed and de-identified, the recorded interviews were played repeatedly while I listened to check and recheck the transcriptions, making corrections as necessary to ensure the accuracy and meaning held within the recorded interview was retained.

The individual data were disassembled into primary patterns and themes, and the themes were refined to succinctly and accurately represent the most important findings using a six-phase thematic analysis procedure described by Braun and Clarke (2006, p. 77–101). Phase One required the researcher to become ‘immersed in’ the data with the goal of comprehending the depth and scope of the content and identifying early patterns (Braun & Clarke, 2006, p. 87–88). To undertake this process, as described above I transcribed the first 6 interviews and checked all 17 transcriptions for accuracy while listening closely and repeatedly to the interviews. I then read and re-read the individual transcripts until I was familiar with their content, early ideas and the
theoretical meanings I gleaned from the data. These ideas were recorded as notes before I began coding the data—the next phase of the thematic process (Braun & Clarke, 2006, p. 88).

Phase Two required me to identify codes: the most basic, meaningful elements of the data that can be grouped (Braun & Clarke, 2006, p. 88). This was done manually for each of the 17 interviews. The narratives were searched for words, ideas and meanings; notes and questions were written on the transcripts and highlighters used to mark and code words, ideas and meanings that appeared relevant to the study aims. The interview data were grouped individually within the families and the interview narrative that related to each code, and the codes were collated in the database, (Braun & Clarke, 2006, p. 89). Please see, Table 4.1 Example of data extracts with codes applied (p.192).
**Table 4.1 Example of data extracts with codes applied (from Braun & Clarke, 2006)**

<table>
<thead>
<tr>
<th>Data extract</th>
<th>Coded for</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think every time they did something there was always hope...there was something....it really did come as a shock at the end when they said well...there’s nothing we can do. (John, Wattle Family)</td>
<td>1. Hope for survival</td>
</tr>
<tr>
<td></td>
<td>2. Communication leading to shock and sense of powerlessness</td>
</tr>
<tr>
<td>He said ‘Oh well I do think it is actually quite serious’. And I was just trying to compute all that… and then it was about 15 minutes after that… he came back out to me and said, ‘quite potentially, this is not survivable’, and I just thought… you are bull-shitting me…you are telling me stories because you’re trying to cover your arse in case something goes wrong. (Avril, Frangipani Family)</td>
<td>1. Shock of new information</td>
</tr>
<tr>
<td></td>
<td>2. Denial of information</td>
</tr>
<tr>
<td></td>
<td>3. Anger and distrust in communicator of bad news</td>
</tr>
<tr>
<td>Because all of us, you know, on one hand, they’re saying ‘Yeah, Stephen’s died’. And then you’re saying. ‘Well, Stephen’s died. Can we have him for spare parts?’ (Julian, Callistemon Family)</td>
<td>1. Disrespect of person</td>
</tr>
<tr>
<td></td>
<td>2. Conflict of interest</td>
</tr>
<tr>
<td>Well, as my husband said, you never give up hope. My sister, my mother was very religious and I go to church but you know … my sister brought down Mary McKillop beads and holy water and we prayed that there would be a miracle. Til the end you… I think that I felt at the end that if she was going to be brain damaged then I didn't want her to live because they're the worst deaths. (Hannah, Blue Bell Family)</td>
<td>1. Hope for a miracle</td>
</tr>
<tr>
<td></td>
<td>2. Over-riding hope to protect from suffering</td>
</tr>
<tr>
<td>It would have been pretty bad knowing that that we’d have to...</td>
<td>1. Delaying death</td>
</tr>
</tbody>
</table>
have him on...to keep him on life support for eighteen hours…for eighteen hours…when... he was… just …itching to go. (Harry, Frangipani Family)

2. Time as suffering

Phase Three (Braun & Clarke, 2006, p. 89–91) requires the researcher to identify the broader themes comprising the next level of data complexity above codes; therefore I grouped similar codes from within each interview using a process of searching the narrative words and passages for meaning and contextual interest, and highlighting these passages using ‘post-it’ notes, memos and pens to highlight and link new and existing themes and codes. This technique was applied across all the interviews and cases.

Table 4.2 Example of codes identified in the Phase 3 analysis

<table>
<thead>
<tr>
<th>Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help</td>
</tr>
<tr>
<td>Time</td>
</tr>
<tr>
<td>Communication</td>
</tr>
<tr>
<td>Transport/ location</td>
</tr>
<tr>
<td>DELAY</td>
</tr>
<tr>
<td>Fear</td>
</tr>
<tr>
<td>Anger</td>
</tr>
<tr>
<td>Expectation hope/ hopeless</td>
</tr>
<tr>
<td>Timing of request</td>
</tr>
<tr>
<td>Witness to testing</td>
</tr>
</tbody>
</table>
This process helped me to identify the broader themes, along with the contextual narratives. The themes were tested for accuracy against the intent and meaning of the participants and the case context before being recorded in the study database. I then trialled and tested concept mapping using large sheets of paper to order the codes, themes, sub-themes and meanings into patterns and categories, before they were photographed, transposed and filed with associated narrative in the study database. These were used to compare the interpreted codes, patterns and themes until the researcher was confident that the data represented participants’ reporting and related to the study aims.

Phase Four requires the researcher to review and refine the themes for consistency and fit to the context and meaning represented in the interviews. The process requires checking for clear distinction between themes, and coherence between and with the other themes, and then requires the researcher to discard themes that are minimally represented or inaccurate (Braun & Clarke, 2006, p. 91–92). Completing this process helped me, as the researcher, to clarify the major themes in the interview data and to review and dispense with those that were less representative. The second part of this phase involved reviewing coded extracts of the narrative data, checking the codes, aligning the data and themes for consistency, and refining the data selection and themes to create a thematic map (Braun & Clarke, 2006, p. 92). The analysis was checked against the meaning of the interviews for accuracy, and across the themes for gaps, errors and missing or inaccurately coded data (Braun & Clarke, 2006).

Once this thematic mapping process was complete, and it aligned with and was consistent with the integrity of the data, Phase Five—a process of further refining the themes—was
undertaken, during which major themes and sub-themes were clarified and their inter-relatedness explicated (Braun & Clarke, 2006, p.92–93). It was important to ensure the identified themes were justified as being ‘internally coherent and consistent’ (Braun & Clarke, 2006, p. 94). The themes were analysed in the context of their supporting narrative, to ensure they were appropriate and representative of the phenomena. A written description of the themes and sub-themes and their relationships was then developed along with descriptive figures to demonstrate their relationships (Braun & Clarke, 2006, p. 92). The major themes and sub-themes of the family decision-making process of deceased organ donation identified in the Phase 5 analysis are shown below in Figure 4.1

*Figure 4.1. Phase 5 Thematic analysis showing major themes associated with family decision-making experiences grouped into ‘Yes’ (consent factors) or ‘No’ (decline factors).*
Phase Six (Braun & Clarke, 2006, p. 93), required me to conduct a final theoretical analysis utilising the eclectic theoretical framework model, completed themes and their narratives, and to document the findings. Each decision was analysed individually and then comparisons were undertaken to analyse and interpret themes identified within the context of each decision, and across multiple decisions guided by the theoretical framework. Importantly, Phase 6 analysis provided an explanation the family decision-making process of deceased organ donation, revealing that the participants’ decision-making process was not a direct, linear event occurring across a measurable continuum of time, or influenced by singular ‘yes’ or ‘no’ factors as initially suggested in the major themes and sub-themes, but a more complex process. The Phase 6 results from this final analytic step will be presented in Section 4.4 (p. 203).

At various points in the study I had the opportunity to share findings and analysis with some participants, who affirmed the authenticity of the transcript data, analysis and interpretations. I shared the findings and interpretations with clinical and academic subject experts and my supervisors, and invited discussion to challenge the analysis and findings throughout the course of the study. The study design is underpinned by this attention to rigour in the collection, analysis, interpretation and presentation of interview data to accurately and sensitively represent the views of the participants.

4.2 Demographic characteristics of participants

Of the nine families that participated in the study, four had declined and five had agreed to deceased organ donation on behalf of a family member. Families were represented in the study by one to five family members that had been involved in the decision-making process. A total of
22 participants, comprising 8 adult males and 14 adult females were interviewed for this study. The participants ranged from ‘young adult’ to ‘retired’ and one family’s decision was discussed individually by participants from three generations of the family in separate interviews. The participants’ relationships to the deceased and to the families’ organ donation decisions are described in Figure 4.2.

*Figure 4.2. Twenty-two decision-making experiences that contributed to nine decisions of deceased organ donation.*
The participants’ relationships to the deceased included two spouses, eight parents, nine siblings, two parents ‘in law’ and one aunt. A summary of their age, relationships to the deceased, and the position in the family of the major influencer of the deceased decision is presented in Table 4. 3. It can be seen in Figure 4.3 and Table 4.3 that women, particularly mothers, played a significant influencing role in this study and their contribution to the decision-making process is an important finding. The interviews revealed that women were the primary decision-makers in eight decisions; however, parents in these cases were unified in their responses and the fathers were active collaborators in two decisions.

*Table 4.3* Family demographics: participant pseudonym, relationship to the deceased and primary decision-maker role

<table>
<thead>
<tr>
<th>Family</th>
<th>Participant’s pseudonym</th>
<th>Participant’s relationship to the deceased</th>
<th>Primary decision-maker in case</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>John, retired</td>
<td>Husband</td>
<td>Husband</td>
</tr>
<tr>
<td>2</td>
<td>Avril, middle aged</td>
<td>Wife</td>
<td>Wife</td>
</tr>
<tr>
<td></td>
<td>Harry, young adult</td>
<td>Son</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ian, young adult</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Jean, retired</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ivan, retired</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Linda, young adult</td>
<td>Sister</td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Sam, middle aged</td>
<td>Father</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Julian, middle aged</td>
<td>Brother</td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Sarah, middle aged</td>
<td>Sister</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helen, young adult</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Jenny, middle aged</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Henry, middle aged</td>
<td>Father</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Hannah, middle aged</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td>7</td>
<td>Ruth, middle aged</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Nicole, young adult</td>
<td>Sister</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Suzanne, young adult</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Louise, middle aged</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Lucy, young adult</td>
<td>Sister</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Brittany, middle aged</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td></td>
<td>Christophe, middle aged</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Joelle, middle aged</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>
In all cases except the pilot study, the participants met the inclusion criterion of having experienced the decision-making process within the previous three-year period. All participants were Australian residents, had good communication skills and were articulate in English. Participants gave no indication of coming from culturally and spiritually diverse or underprivileged communities. All participants exhibited characteristics of a range of social and economic success, in that all reported being employed, retired or in student roles. Several participants reported how family and friends with professional backgrounds contributed their professional knowledge in the areas of health care, law and education, to the family decision-making process.

Each of the deceased played a major role in their families’ lives and contributed to the social and emotional wellbeing of their families; some also played a provider role. The wishes of the deceased were deeply significant to the participants, and when known, participants actively sought to honour their family member’s decisions. As mentioned previously, ‘family’ members are defined by the family and may comprise people without a legally recognised relationship to the deceased. In this study ‘family members’ without a legally recognised relationship to the deceased; nonetheless contributed to the decision-making process and organ donation decision outcomes.

There was a risk that complex personal situations or traumatic circumstances leading to the death of the deceased could cause families to suffer complicated grief: for example, four families had previously experienced death within the close family circle, some of which had been recent. Two deceased organ donation decisions followed suicide. Additionally, several
families had suffered instability from broken relationships. All of the deceased died suddenly and unexpectedly. Six of the deaths involved trauma-related injuries, two occurred following hypoxic brain injury, and in one decision, ‘other’ causes of physiological failure led to the death.

The geographic location of the crisis, the requirement for patient transfer and the location of critical care services where deceased organ donation decisions were made were a significant contextual element for family experiences in this study. Figure 4.5 (below) demonstrates that many of the crisis events that led to the deaths in the sample occurred in regional locations requiring the patient to be transported long distances to and between hospitals. This information suggests that distance and travel may have played a role in the decision-making experience of the families. The sample comprised families from five of Australia’s eight states and territories.

*Figure 4.5. Geographical context of crisis event and declaration of death*

The clinical circumstances that led to the family and health professionals’ discussions about organ donation included four decisions where families were asked to donate their relatives’ organs before death was confirmed, in the context of DCD processes. Five families made a decision in the context of DBD processes, however, brain death had not been declared prior to
four of these decisions. This included a potential DBD situation where, despite the families' consent to donate, circulatory arrest intervened before brain death could be determined (see Figure 4.6). Therefore, in all but one death, the families were involved in donation decision-making before death was confirmed.

Figure 4.6. Process used to determine death in the nine family decisions.

Two families were asked to consider organ donation by Emergency doctors whilst their family member was being treated in the Emergency Department. Both families agreed. Each family’s response was provided by the mother of the critically injured patient, and their responses were informed by the mother’s knowledge of their donation intentions. One of these decisions resulted in organ donation following the DCD pathway. In the other decision, brain death was anticipated; despite the family’s desire to donate, organ donation did not proceed due to circulatory collapse before brain death was confirmed or organ donation processes instituted (see Figure 4.7, p.202).

Donation proceeded in three other consent decisions made following family discussions with doctors and nurses in intensive care units. Of these, 2 donations followed DBD pathways and another was DCD. Therefore, from nine deaths, 5 families agreed to donation, four patients donated organs, 2 following DCD and two following DBD processes. One patient did not donate
because they suffered circulatory arrest and death before organ donation processes could be arranged as described in Figure 4.7 (below).

*Figure 4.7. Consent decision outcomes.*

The period of time that elapsed from when family members became aware of the crisis until they left the hospital following the death and donation decision, ranged from approximately 12 hours to 120 hours (5 days). Eight of the nine deaths were referred for coronial investigation, and therefore coronial approval was required if organ donation was to proceed.

**4.3 Pre-event attitudes and expectations**

As discussed in earlier chapters, the disparity between community support for organ donation and actual consent rates for organ donation is significant. Importantly, all participant decision-makers provided evidence that they supported *in principle* the idea of organ donation, and described benefits ascribed to organ donation. Despite this understanding, in four deaths the families declined donation, and within this group, two families did so despite believing their family member may have wished to donate. Therefore, these decisions fell within the category described in public debate as *over-turning* their relatives wish to donate. The refusals were influenced by their dying/deceased loved one- and family-prioritised needs.

Of the nine deaths, all participants from five families were certain of their family member’s donation wishes either through previous discussion or from written evidence such as
driver’s license or donor registration. Despite this, the participants demonstrated notable confusion about the purpose and role of donor designation on the deceased’s driver’s licence or on the AODR when making the deceased donation decisions. Ten participants that knew their loved one had documented their decision to donate their organs after death described disappointment that the registry information was not used more effectively in their decision-making experiences, believing that registry information was not checked. They therefore presumed the wishes of the deceased were not considered unless raised by their family. The participants explained that they appreciated the deceased had or may have documented their wishes, but were disappointed when this information was not discussed with the family; believing this would have honoured their loved one and provided them with decision-making support.

4.4 The results of thematic analysis of the interviews with decision-makers

Seventeen individual and group interviews were conducted with the 22 participants. Three major themes and six sub-themes depicting the family decision-making process of deceased organ donation were identified from the interviews. Importantly, the participants’ decision-making process was not a direct, linear event, or influenced by singular factors despite occurring across a measurable continuum of time. Most participants described a complex experience of decision-making that encompassed multiple events, and included new and unexpected information and meanings. The participants described an experience during which their previous view of deceased organ donation decision-making shifted. The decision-makers balanced competing consent and decline factors while traversing the continuum of the decision experience. In several cases, families came to more than one decision as they encountered new
information. For example, in one decision-making process, the family first agreed to donate, then withdrew their consent, and then agreed for donation to proceed as their final decision.

The deceased organ donation decision-making process is a complex multifaceted experience for families. An overarching representation of the family decision-making process of deceased organ donation is presented in Figure 4.8 (p.208), in which the pink arrow underpins all the activities and understandings implicit in the decision-making process, and represents the inexorable progress of time. Four decision points were identified in this study and are designated on the timeline, which encompasses the continuum of the decision-making process.

The four decision points comprise 1) pre-event attitudes and expectations of participants, deceased family member and family; 2) the point at which the family decision-maker realises that the death is inevitable; 3) the point at which the decision-maker discusses organ donation with health professionals, and 4) the post-event, ongoing attitudes and expectations of the decision-makers. Decision points 2 and 3 occurred in the reverse order for some participants because organ donation was discussed before the decision-maker had accepted that death was inevitable. For these families the discussion about organ donation helped them comprehend the terrible nature of the situation.

The participants’ progress forward is represented by the blue arrow in Figure 4.8. They described experiences and feelings that suggested that preceding the crisis they had felt they were in control of their lives and decisions, travelling smoothly until the event that precipitated their family member’s death. Upon becoming aware of the danger to their family members, participants seemed to fight to try to maintain control of their world. The crisis erupted without
warning, generating a tempest that enveloped the participants and their family members, represented on the diagram as waves. The participants sought to protect their family member, which could be likened to navigating huge waves. They tried to regain control within this perilous situation, starting from the wave’s base where the enormity of the event and its implications towered over them, and threatened to drown them. Participants fought to find strength and information via hope and trust to climb the waves. When almost atop of the wave, it was as if the participants began to believe they had gained some control of their circumstances. As they crested the wave, most participants believed they could use its power to move forward.

One family succeeded and was carried safely through the experience reporting minimal buffeting and finding validation for their deep hope and trust. Members of other family’s suddenly encountered unexpected information that brought them crashing down, and into the trough of the wave, whereupon they found another wave towering above. The cycle was then repeated for some families that once again undertook the torturous effort to summon the will and strength to mount the wave in the face of the new information. This level of effort typified the work involved for participants throughout their decision-making experience.

The themes and sub-themes representing the families’ decision-making process are also depicted in Figure 4.8. The themes represent the continuum of the decision-making process, commencing with the event that led to the death and the families experience in the hospital, followed by themes associated with consent or refusal decisions as mentioned previously (Figure 4.1, p. 195). During the experience, participants tried to orientate themselves to the changing circumstances and plan a way forward, only to find that they felt as though they were In the fog
drowning requiring information and guidance to help manage their shock, fear and confusion. The need for family survival appeared to drive women and particularly mothers to lead decision-making, and most families deferred their decision to the matriarch, represented within the theme, *It’s all up to Mum*. In some circumstances, the decision-maker’s trust in the staff was misplaced and they and their family were left to help themselves or drown, which was experienced as a *Harvesting of humanity*. 

These three major themes apply to all the families whether they agreed or declined donation. The first major theme, *In the fog drowning*, refers to decision-makers’ experiences of deceased organ donation decision-making. This theme was delineated by the crisis event leading to death, the critical illness, the diagnosis of death, the decision and its consequences. The theme encompasses the shock, confusion and fear described by the participants as they struggled to conceptualise the life threatening situation and find help for their family member. The two sub-themes comprise *This is how it happens* and *Stop all the clocks*. These sub-themes point to the sense of powerlessness that these families experienced, fitting into the needs of the organisation, and feeling the inexorable movement of time throughout their decision-making experience as they worked with their family to protect their loved one. The second major theme represents the decision influencers, *It’s all up to Mum*, and its two sub-themes, *Well you never give up hope* and *Trust protected*, which were found to influence final donation decisions. The third major theme, *Harvesting humanity*, and the two sub-themes, *Sack of body parts* and *Sacrificing peace at death* were the theme and sub-themes that represented regret and barriers to deceased organ donation.
‘Traffic’ light colours were applied to the diagram to clearly delineate the major themes, which are represented as clouds. Orange represents the decision-makers’ situational context of shock, fear, confusion and precaution. Green represents themes associated with consent decisions, and red represents themes associated with barriers to deceased organ donation and decline decisions. The diagram is ascribed with arrows that represent the decision-makers’ progression through the experience and decisions.

One family offered donation and never altered their view. One family declined to donate but reflected they may have agreed under different circumstances. Another family that declined donation initially then agreed to donate, and concluded by declining donation. Two families sought information about organ donation, or offered donation, before both families declined donation. One family agreed to donation, then withheld their consent, and ultimately allowed donation to proceed. Two families agreed to donation but found the subsequent events so distressing that they almost withdrew their consent (but allowed it to proceed), and still feel traumatised by their experience. Finally, one family agreed to donation without understanding the process, which caused them subsequent distress despite their disappointment that the donation was unable to proceed.
Figure 4.8. An overarching representation of the family decision-making process of deceased organ donation in relation to the model of decision-making.
For clarity, the findings will now be presented within the three major themes *In the fog drowning, It’s all up to Mum, Harvesting humanity* and their sub-themes (Figure 4.9, below). The themes are bound by the family deceased organ donation decision-making process that encompassed five key events for the decision-makers, 1) the crisis event that caused the critical injury; 2) the recognition that death was inevitable; 3) the diagnosis of death; 4) the organ donation decision and 5) its consequences. The findings within each major theme and sub-theme will therefore be presented in this chronological order.

*Figure 4.9.* The three major themes and sub-themes of the family decision-making process of deceased organ donation
4.4.1 Theme One: *In the fog drowning*

The major theme *In the fog drowning* and its two sub-themes *This is how it happened* and *Stop all the clocks* are represented in Figure 4.10.

*Figure 4.10. Theme 1. In the fog drowning* and its sub-themes.

The major theme *In the fog drowning* and its sub-themes *This is how it happens* and *Stop all the clocks* specifically relate to all participants experience of the critical injury, hospitalisation and death of a loved one. The theme encompasses participants descriptions of first, the shock; second, the fear; and third, the confusion that engulfed the families and continued throughout their decision-making experience. This overarching theme was bounded by the crisis event that caused the critical injury, the recognition that death was inevitable, the diagnosis of death, the organ donation decision and its consequences. The name of this theme is drawn from a comment made by Louise, who described how she felt after hearing that her son was critically injured: *I think you’re just stunned. I think from the time you’re told you just go into a fog.*
Many participant’s spoke of being a first responder or witness to the event that led to the death. This was an important contextual influence in the decision-making process for the participants in this study. It was evident in six deaths that family members had witnessed the trauma of the pre-hospital event leading to death, with a key decision-maker present pre-hospital in five of those deaths: and then my heart sank and I just heard screaming. I just ran out there (Jenny, mother of deceased). Avril described finding her injured husband: I rolled him on his side and then I realised he wasn’t breathing, and I realised that there was a lot of blood.

Participants described trying to get help for their loved one. Brittany described how bystanders tried to help her daughter: They did what they could. It took well over an hour before an ambulance got there (Brittany). Another mother told how health professionals were slow to respond when a family member found and sought help for her critically injured daughter: He [husband of the deceased] had to call for help. They said to be quiet because he was singing out and he said for them to get in there. It was terrible (Hannah).

Participants intervened and tried to carry out health professionals directions whilst waiting for help to arrive. Julian described his distress in finding his brother unconscious and fitting. He summoned the ambulance and while awaiting their arrival, he followed the operator’s instructions- that did not make sense to him:

I stayed with him. But from the minute I saw him, he was like ‘Humpty Dumpty’. All the kings’ horses and all the kings’ men just aren’t going to do it [help him recover]. And
here’s this operator saying, ‘Sit him up’. I said, ‘He’s convulsing. I can’t sit him up’ …

But I sat him up, and he starts spitting blood (Julian, brother of deceased).

Some participants struggled to find information in the first few hours when their loved one was being stabilised in emergency departments. One family described their desperation as they fearfully listened from behind closed doors as emergency staff tried to secure an airway, waiting for news of their loved one’s condition, and trying to understand what was happening:

We weren’t allowed in. You could hear that the doctor was really struggling, and there was a fair bit of noise going on. And then another doctor came in and said they were having a lot of trouble intubating him (Ruth- mother of deceased).

Participants became more fearful and anxious if they believed that information about their family member’s condition was being withheld, or if they believed the staff knew the situation was critical but were unwilling to engage in discussion or to explain the extent of the injury:

They explained that it was a very severe injury, but I said, ‘Well how bad?’ and they said, ‘Oh well, we don’t really know,’ and one of the Nurses on duty was a friend of ours, and I said to her, ‘How bad?’ But I asked her in front of everybody else and she just shook her head and said, ‘Oh look, it’s not for me to say’. And so I knew then that it was really bad, because otherwise if there was any hope, she would have reassured me (Ruth, mother of deceased).

The majority of participants expressed difficulty in managing the emotional, physical and cognitive demands of their situation. One participant recalled recognising that he was in shock,
and remembered questioning his ability to survive the experience: *You’re just in a state of shock. Wondering how you’re going to get through it* (Ian, son of deceased).

It became apparent that many of the decision-makers had been without sleep or rest for prolonged periods while transitioning the decision-making process: *At this point we hadn’t been to bed from the night before, so we were sleep deprived anyway. We’d just spent five hours in the car* (Louise). Lucy finished Louise’s sentence: *Just running on pure adrenalin* (Lucy). Some participants described how it was difficult to eat or drink because of feelings of fear caused by their circumstances. Other participants recalled being grateful when nurses suggested they should leave the bedside to take care of their own and other family members’ physical needs: *That was fair enough, because we actually needed to go and eat* (Brittany).

The participants spoke of their fundamental need for clear information about their loved one’s situation. However, despite seeking out this information, some participants were fearful about receiving the information and its implications: *I was floundering for information, information that I didn’t really want to know* (Ruth, mother of deceased). Many sought to clarify their understanding of the care provided without knowing how to approach the questions: *I think in that state you don’t know what you should be asking, and you’re in so much of a fog that you don’t know what to ask* (Louise, mother of deceased).

Some participants had difficulty in understanding the severity of their loved one’s condition. They spoke about wanting more information and revealed their belief that if they had
received the same information that was available to the health professionals, they would have been better equipped to cope with the situation and to make decisions:

*I think to them it was really obvious that he had no chance of survival, and that it was only going to be a matter of a short period of time. But to us, we didn’t know that, because we hadn’t seen any pictures, we didn’t see any results of the CAT scans* (Ruth, mother of deceased).

The decisions were made within the clinical context of the circulatory or neurological declaration of death. This context determined if DCD or DBD processes of organ donation were considered. The information about these processes and their relation to the death of the loved one was provided to the participants by either the bedside nurse or a treating doctor. This sometimes required the family member to ask for information about what would be required for organ donation - particularly if the family considered organ donation before staff had mentioned the possibility. Some participants did not receive the information they sought, and when interviewed were still confused about the process of organ donation.

Participants spoke about the events leading to the confirmation of death and particularly focused on their communication with the health professionals responsible for treating their family member. Some participants were unable to understand the treatment goals or the prognosis despite their interactions with health professionals.

*I don’t think we were ever guided through what was wrong with ‘Kieran’ [pseudonym]. It was like here’s the scan, here’s what’s happened, and from that point on you’re on the*
organ donation thing. When we look back we [realise that] we really got funnelled down and pushed down this track without enough information (Louise, mother of deceased).

Words such as ‘ventilator’, brain death’ and ‘intensivist’ that are commonly used in the critical care environment created confusion for many of the participants who appeared to have a poor understanding of their meaning. The participants were not familiar with the names or the specialist roles of doctors and nurses that work in either the emergency or ICU’s, or those of the donation staff. They were unfamiliar with the skills they hold and the terminology that surrounds much of the treatment provided to the critically ill patients: So that was like … we met this intensivist,[doctor] I didn’t know what his role really was, but he did say that he was there to care for ‘Hamish’ [pseudonym] (Ruth, mother of deceased). Ruth’s family spoke about how euphemisms were used to indicate their family member’s prognosis which created misunderstanding. This was compounded when the health team failed to provide the family with information about how death was diagnosed and the clinical processes required for organ donation. This poor communication contributed to the families’ fear and confusion: We did not understand. We knew they said ‘Hamish’ [pseudonym] will decide’, but I don’t think they actually said that if he goes to cardiac arrest he can’t be a donor (Suzanne, sister of deceased).

Most families were told about the organ donation process after they had agreed to organ donation. The information given to the families at that point in time was necessarily specific to the clinical condition of the patient at the time of the discussion with the health professionals. Any changes in the dying patient’s condition that resulted in changes to the clinical context of the diagnosis of death made the situation more confusing for the participants. For example,
participants gave examples of family members who were thought to be brain dead but in fact on testing, were not; or those who were not brain dead but displayed signs that suggested brain death had occurred. These disconcerting events contributed to fear and confusion particularly if clinical testing was not shown to the decision-makers: ‘Well how do you know he’s not brain dead, like how do you know?’ They said, ‘Well we do some tests, one of them is that they put the cold water in the ear’. I said, ‘So that’s it?’ and they said, ‘Oh, if the pupils are fixed and dilated’ (Ruth, mother of deceased). Ruth explained that she and her family were not shown the testing, and therefore had difficulty conceptualising the futility of the situation: They didn’t show us that his pupils were fixed and dilated (Ruth, mother of deceased).

Most participants commented that they felt unprepared for the shock of the events and the responsibility for making significant decisions such as organ donation without experience or knowledge to draw from: In our family we’ve never lost anyone young and so donating had never, ever come up (Hannah, mother of deceased). The participants gave descriptions that suggested they were alert to danger, constantly re-evaluating the complex circumstances, trying to make sense of what they saw and heard, and taking great caution. Like many participants, Ruth blamed herself for failing to gain a clear understanding of what the organ donation process entailed before agreeing to donation in her personal documentation, when encouraging her family to sign the donation register- and when telling an emergency doctor she’d agree to donate her dying sons organs: I was just annoyed that I didn’t know what I needed to know … Why can’t I understand? (Ruth).
The sense of confusion about organ donation processes was not confined to the participants; staff in some settings also seemed shocked and confused by the idea. A participant spoke about how his family had offered organ donation; however, after making the offer they sensed that the health professionals were also uncertain of the requirements for organ donation. This perception contributed to a sense of confusion for this family who subsequently withdrew their offer: *But I remember there was some sort of confusion about the whole organ donation [process] and the team coming up … [staff were delayed in providing information to the family about the process]. I was wondering are they going to come back? Because we weren’t going to make a decision about organ donation until we knew how it worked* (Harry, son of deceased).

The idea of their family member being kept on a ventilator while dying or dead and awaiting the arrival of the organ donation surgical team was new, unexpected and disturbing information to many of the participants. The participants spoke about previously believing that the donation operative process would occur following the removal of life support interventions in the ICU. Participants had assumed the body (without circulation) would be quickly transferred to the operating theatre for surgery. These ideas are more consistent with DCD practices but also reveal the confusion experienced by participants in trying to understand brain death: *I know what a coma is; I didn’t really understand the term ‘brain death’* (Ruth, mother of deceased).

Participants described their shock as they came to the realisation that their assumptions about organ donation processes differed to the reality. This confusion angered some participants who felt unprepared for the new information and the cognitive and emotional effort required to comprehend it: *I think we had a bit of anger about the lack of knowledge about the process. It*
was an unnecessary trauma at a time that was already filled with lots of grief, and it just added to it (Brittany, mother of deceased).

Some participants expressed a sense of loneliness and feeling deserted after the death when the body was taken away for DCD: *And then after the machines were turned off it was probably only about five minutes, and then they took him away and they left us standing in the empty space, and no-one came to us* (Louise, mother of deceased).

Some participants described that having viewed their relative’s body for a last time, leaving the body at the hospital was a forced, final separation that made them feel that they were deserting their loved one: *Walking out of hospital without him. It’s just horrendous leaving your child there with strangers* (Jenny, mother of deceased). Sam (father of deceased) described a devastating sense of loneliness as he prepared to leave the hospital: *and I was left wandering around ... and he’s so gone.*

Many donor and non-donor participants remained confused after the death about the treatment received by their family member when they reflected on their experiences. Some participants revealed that despite discussing the organ donation requirements with doctors and nurses, they remained perplexed by the logistics and requirements of the organ donation process: *It was not about deciding, that was a given for us. It was, why don’t I know what organs do they take, what would he look like, when do they stop?* (Ruth, mother of deceased). Another participant questioned: *I don’t even know, do they take his whole body down to [large city]? Do the recipients fly to [small regional centre] for the operation?* (Harry, son of deceased).
This confusion appears to have complicated the bereavement of some families and left some with a lingering fear regarding the care their loved one received, and of organ donation processes. Most families did not have a follow-up meeting to discuss and clarify their understanding of the events surrounding the death, with the health professionals involved in their family members’ care. The families that declined organ donation reported that they received no bereavement support or follow-up from the organ donation organisation or the treating hospital, other than the care routinely provided through the coronial system and funeral directors unless the participants initiated the communication. Even then, some received no response to their requests.

Several participants expressed the view that being asked to decide to donate their family member’s organs was a significant impost: *It’s a big ask* (Hannah, mother of the deceased). This view was supported by other participants including Harry, who emphasised that because the death is unexpected, it will always be difficult for a family to make a deceased organ donation decision: *Something like that is never going to be a good situation. It’s always going to be chaotic and the family is always going to be in a state of mind where it couldn’t get worse* (Harry, son of deceased).

In conclusion, the theme *In the fog drowning* is an intrinsically negative theme because it encompassed the experience of 1) the shock; 2) the fear, and 3) the confusion that all families encountered with the unexpected critical injury and death of a family member. This theme underpins all the family experiences of organ donation decision-making in this study. Each time the participants received new information that challenged, conflicted or contradicted their
assumptions- the fog returned. The families responded by first, seeking help from health care professionals; second, seeking proximity to their loved one to check that everything was being done to help their loved one; and third seeking information to help them understand the unfolding events. The evolving circumstances required families to adapt to conflicting information, over-turned assumptions and uncertainty about the future.

The findings suggest that all families require help from the first moments of the crisis and throughout the experience in order to 1) attend to the needs of their dying family member; 2) to be assured their family member is receiving competent professional care, and 3) to know that everything possible is done to help their family member. The families in this study sought clear information and visual evidence to assure them that their family members’ needs were of paramount importance to the health care team. The families needed support to understand what they were seeing and hearing; guidance about what to anticipate; and support for their bodily needs. Finally, they needed debriefing after the events by health professionals regarding what they had experienced. These decision-makers asked for the timely provision of professional assistance starting with first responders; proximity to the patient- supported by clear information; the provision of organisational support to contact their relatives; public information about the diagnosis of death and the processes of organ donation; and professional support to separate from their relatives’ body and to understand what they had experienced.

4.4.1.1 Sub-theme 1.1: This is how it happens

The sub-theme This is how it happens encompassed all participants experience of first, bringing the family together for support and end of life decision-making; second, feeling trapped
in the situation, trying to ‘do the right thing’ to fit into hospital environments; and third, trying to anticipate and comply with the health organisations requirements of them, their dying relative and organ donation. The participants spoke about depending on family members and close friends to help them face the crisis by sharing the burden of decision-making responsibilities. This finding related to all families, including those where the participants spoke about difficult circumstances such as damaged relationships within the family that complicated the participants’ experience of grief and decision-making. The name of the theme was drawn from all the participants experience that there was inevitability about the way the deceased organ donation decision-making experience unfurled- that pointed to a predictable sequence that the families were required to comply with, without preparation or warning.

Most participants indicated that their families needed transparency to understand the extent of their relatives’ injuries and the likelihood of death. Once it became medically obvious that their family member’s condition was not survivable, they wanted a clear understanding of the situation. Participants that witnessed the critical events leading to death appeared to quickly conceptualise the gravity of the situation, and when health professionals used terms such as ‘un-survivable’ the decision-makers were better able to understand the implications: But when he said un-survivable, I thought, oh this is serious (Avril, wife of deceased). This information allowed them to embark on their tasks of preparing for difficult decisions, of honouring their relationships, and preparing for the death. Notifying their family and friends was seen as a critical but onerous task. The families needed to summon other family members for support, for decision-making and to say goodbye: I broke it to my brother [that their father was dying] that’s how it was (Harry, son of deceased).
Most participants described feeling frustrated that they did not have the ability to alter the inexorable progression of events they encountered from the moment of the critical injury until after the implications of their organ donation decision became evident. Ruth describes that when the emergency department doctor explained that her son’s condition was inoperable, the information made her realise the situation was critical, and this impelled her to gather her family: *He couldn’t be operated on and he was more than likely going to die and if we wanted to contact anyone else, now was the time to do it* (Ruth, mother of deceased).

Some participants encountered significant logistical difficulties as they tried to gather their family to face the crisis. Some participants described making arrangements for trusted friends to support vulnerable family members when the news was imparted; or of waking relatives with the news: *Well I didn’t actually answer the phone. My brother came around and woke me up* (Ian, son of deceased). The participants spoke of anxiously trying to reach family and friends to break the bad news, using local and long distant telephone calls and in arranging travel. *So that was the hardest call I had to make* (Avril, wife of deceased). Another participant stated that informing the mother of the deceased was a terrible task: *The worst thing I had to do was ring her and tell her … You know, that was one of the, one of the hardest things I've ever had to do* (Julian, brother of deceased). Louise also emphasised the difficulty she faced in telling her children their brother was dying: *I had to go and wake the two kids up. Which is probably the hardest thing, especially when you wake them up out of a dead sleep and say, we have to go, your brother’s going to die. We want to go and say good-bye* (Louise, mother of deceased).
In some circumstances, families used police to find family members. Linda, whose brother was dying, received a call from a friend: *I’ve just had a call from the cops; they’re out looking for you.* Long distances complicated travel for some participants who described how they and their family moved quickly to overcome barriers involved in bringing the family to where their dying relative was located. Three families had relatives who travelled from distant international locations to be at the bedside—two families required help from the Department of Foreign Affairs to expedite their travel. Some participants spoke of family members travelling without sleep, in terror and with bodily needs forgotten. Others explained how their relatives required help to perform the most basic activities upon hearing the news: *He [father of deceased] was working and they came and called him in. They said he was running around in circles so they had to pack his port and everything for him. He didn’t know whether he was Arthur or Martha* (Hannah, mother of deceased).

The participants spoke about feeling comforted by their family and close friends at the hospital, and explained that their support made it easier to make decisions. Participants also sought the help of family members and friends that had professional knowledge of medicine and nursing to help them interpret the unfolding events so they were able to assure themselves they understood the meaning of what they were being told: *And he was talking to them and then translating the medical jargon into something we could understand* (Brittany, mother of deceased). The participants gathered support from within their family to decipher the information. Ruth describes her call to a relative—a doctor—who when asking Ruth for more detail about the clinical condition of their family member responded in shock, leaving Ruth under no illusions about how dire the situation was: *So I said, ‘Oh, his pupils are fixed and*
dilated,’ and the scream that she let off was just … like that was enough for me, like I really then knew (Ruth, mother of deceased).

Some participants spoke about the differing views about organ donation held within the family, by family members at the hospital who shared in the decision-making experience. In some situations the decision-makers welcomed their involvement, in other decisions the participants described a sense of frustration caused by their feeling of obligation to include the other family members at the bedside. In several deaths the differing views held within the family about donation contributed to heated discussion that was resolved by the family, within the family. Despite these experiences, the participants were all of the view that they needed their family and friends to be with them, helping, supporting and guiding them: I think what made such a big difference was our family just all got there within a few days (Brittany, mother of deceased).

The participants viewed their deceased organ donation decision-making experience as inextricably entwined with the dying of their loved one and the professional care they received. The participants were familiar with the idea of life-sustaining technology and its application in critical illness. They were also familiar with the idea that life-sustaining treatment could be withdrawn before the declaration of death; this contributed to the sense of urgency in gathering the family: We called the boys. We let them know that we needed them to come up right away before life support was pulled (Ivan, father–in-law of deceased).
The participants were conscious they were not alone in their experiences of caring for critically ill relatives. Many spoke about not wanting to intrude or have their own needs supersede the needs of others in the intensive care environment whose loved ones were also receiving treatment. Participants particularly commented on environments where there was little space to gather. They noticed when other families were asked to leave waiting rooms to allow their own family privacy to speak with the staff. Some participants described their discomfort regarding this situation, believing they had contributed to another family’s suffering. They suggested that actions taken by the health professionals to free the room for their use were taken specifically because of the need to discuss organ donation: Where we were, other people who had someone in ICU were tipped out so we could have the privacy (Julian, brother of deceased). Another family had a similar experience: We went into this little room … where people had been kicked out (Linda, sister of deceased).

Participants all spoke of their efforts to ‘fit in’ to the hospital environment and to access information. The nursing and medical staff who guided the family members in and out of the critical care environments were valued and their actions were remembered. In most instances, health professionals’ interventions helped the families form a clearer understanding of the clinical environment and to prepare for death: We sat down and the head nurse of ICU spoke to us, and told us what to expect (Harry, son of deceased).

The discussion that took place between the treating team and the decision-makers appeared to have a ‘serendipitous’ quality involving whoever happened to be there at the time for many of the donation discussions. The role of ‘family’ in making the decision was a nebulous
idea because some of the family meetings comprised large numbers of people, and in some circumstances many without a ‘blood’ relationship were present: *You know, an extremely difficult situation, because, Stephen wasn’t our flesh and blood, yet we were treated as if we were …* But, *it was like he was an extension of our family. So, we felt like he was family* (Julian, brother of deceased).

The participants were reliant on the bedside nurses’ interpretations of the terminology, equipment, alarms and other clinical activities. Most participants spoke about how the nurses or doctors tried to explain the technology that was involved in the care of their family member. This support lessoned the families’ distress while in vigil at the bedside. The participants described interactions with health professionals who were tasked to care for the patient or were friends or acquaintances of the family. Regardless of the explainer’s background, the effort was valued by the participants:

*You know when you hear ‘beep, beep, beep’, and you think, oh, shivers there’s something wrong. She [the nurse] sat with me and explained that this just means this, or that. You know, the heart beat is okay, and the pulse is a bit low, or a bit high. She just read it all out. She just sat there which was really good* (Linda, sister of deceased).

The quality of the relationship between the decision-makers and the health professionals appeared to closely align with the interest shown by health professionals in the needs of the patient and their family. Some participants described how the doctors provided information, ‘testing’, ‘hovering’ and ‘coming in and out’. 
Some participants spoke of impersonal conversations in corridors between the doctors and participants, where doctors were described as having: drifted in and drifted away from the bedside without appearing to connect with the patient, participant or family: *I think it was just one of those cases where he’s [the doctor] floating in and floating around the ward sort of thing, nothing …* (Louise, mother of deceased). The relationships between the medical and nursing staff were particularly commented on by one participant, who perceived that the nurse’s role included interpreting the doctors’ communications: *They’re normally the ones where the doctor might bark some orders, and then the nurse is the one that explains most of the information* (Nicole, sister of deceased).

Several participants spoke about being glad they could be present at the bedside, but found that it was difficult to be there: *We sat with him for about twenty minutes or so. It was hard. It was a bit weird, it was distant in a lot of ways and it was uncomfortable. But I wouldn’t have had it any other way. We could touch him and hold his hand which was good* (Ian, son of deceased).

Emergency surgery was performed prior to two deaths in an effort to save the dying patients. In both situations the families came into contact with the staff from the operating theatre. The families indicated that they knew the surgery was a desperate measure and was unlikely to change the outcome. Following the unsuccessful surgery, the decision-makers from both families agreed to organ donation. One organ donation decision was made after the family had been informed of the brain death, Brittany [mother of deceased] described how she came to understand that her loved one could not survive: *Then he [doctor] came back to us and said,*
we expected, that the tests now showed conclusively that she was brain dead, and there was no hope of resuscitation (Brittany, mother of deceased). Decision-makers from the other family had been witness to the events leading to the impending death, and realising that death was inevitable, offered donation. The families in both decisions explained that they were comforted in knowing that everything possible was done to save their loved one:

*They took us into a room and said to us we’ve done everything that we can and they said normal brain pressure is under ten, you know between ten and 30 is brain damage of increasing severity and over 30 is un-survivable. He [doctor] said ‘Tim’s [pseudonym] had gone to over 100. I think in the end he said it had gone to over 150. So we knew then that this wasn’t going to be a miraculous recovery* (Henry, father of deceased).

Most participants indicated that it was important for their decision-making to know that their family member’s condition was un-survivable. Most explained that they knew their family member’s bodies were being supported by life support technology and understood they were brain dead before the testing was completed. Some families were able to identify that although their loved ones condition was not survivable, they had not met the criteria for declaring brain death: *He wasn’t brain dead … yet* (Sally). The decision-makers’ use of the terminology ‘life support’ did not seem to be associated with any confusion about the prognosis of death, or a belief that their loved one was still alive in person: *I think the best summary is that from that evening in the hospital we knew she was on life support and brain dead* (Christophe, father of deceased). One family decided to leave their dying relative who was not brain dead prior to the planned removal of ‘life sustaining treatment’ believing he was already ‘dead’ in person: *We didn’t stay around to watch the heart beat go flat, we’d made the decision and we left. That’s*
him breathing, that’s him not breathing. We left him alive on life support (Harry, son of deceased).

Several participants spoke about sensing their loved one (who still showed signs of life), had ‘gone’-, leaving what participants described as a ‘vessel’ or ‘shell’: You just knew he wasn’t there. It was just the shell. Just the machines and stuff. I can understand that they were keeping him, the body alive [after declaration of brain death and before donation surgery] (Helen, sister of deceased). Linda commented: You could tell he wasn’t there anymore … he just wasn’t there (sister of deceased).

The participants whose family members’ death had been diagnosed by using brain death criteria were content that their loved one was dead and could not recover, which suggested that they understood the idea of neurological death. Most commented that they had confidence in the doctors’ judgement: I thought she was a competent doctor (Sam, father of deceased). Two participants were able to describe physiological aspects of brain death and described how the swelling of the brain had caused the brain to die: The brain must have been a hundred per cent swollen; because the brain had swollen so much that it had pushed down the spinal cord causing brain death. That’s how it happened (Linda, sister of deceased).

Most participants whose family members were confirmed dead using circulatory criteria, mentioned that if their loved one had remained on ‘life support’ brain death may have become apparent.; however, some participants suggested the withdrawal of life-sustaining treatment was preferable to waiting for brain death because they equated ‘life support’ with continued suffering.
and a risk of surviving in a diminished state: *He had no chance of recovering to the person he was, and if he made it, the slight chance he made it through and was able to live without life support, then he would not be the person he was, he would be a vegetable* (Harry, son of deceased). Most participants whose family member was declared brain dead described a sense of relief in hearing that outcome: *So they pronounced him brain dead. And we thought, thank God for that* (Linda, sister of deceased). One participant believed that the declaration of brain death was an administrative necessity to enable treatment to be discontinued: *They came back into the room and said the doctor has now certified and completed [death certification] as by law … because you can’t turn it off without certifying* (Sam, father of deceased).

Many participants spoke about proactively trying to find out information about the organ donation process and what it comprised, before being asked to make a decision. Linda described how her mother sought information about the organ donation process from the night shift nurse at the bedside: *So Mum said, ‘Can I ask you about organ donation? What’s the process?’ Mum wanted to get the information about what the process is and she got it from the nurse at the end of the bed* (Linda, sister of deceased).

The differing requirements of DCD or DBD significantly impacted on the families’ experience when they separated from their family member’s body to allow the transfer to the operating theatre for organ donation surgery. The process of DCD appeared to broadly fit the families’ expectations of deceased organ donation processes. Participants that agreed to DCD appeared better equipped to accept the donation process. In one case the doctor was particularly valued for showing emotion: *The doctor was even crying her eyes out when she turned the
machines off (Henry, father of deceased). Importantly, the families that agreed to DCD were surprised by the short period between when death was declared and when the body was taken, and emphasised that families need good support in this process: *I didn’t realise how short that window of opportunity was. I think having that explained properly probably helped, because if that wasn’t explained or you didn’t understand it then it would feel like, get out of the way we need these organs* (Jenny, Mother of deceased).

As previously mentioned, two participants provided a clear interpretation of brain death in the context of their loved one’s condition, and other participants appeared to understand that the declaration of brain death indicated that there was no hope of the person ever recovering. Some participants appeared to associate ‘brain death’ as equivalent to being in a ‘vegetative state,’ revealing the idea that despite being confirmed brain dead, some participants believed that death really occurred with the cessation of heart beat.

Once the participants had made decisions to either agree or to decline the donation of their family member’s organs and they had communicated their decisions to the professionals involved in the care of their loved one, they described being grateful if given acknowledgement for their decision. Some participant’s spoke of making the decision based on their family member’s wishes, some decisions appeared to decide from ‘the heart’ of the decision-maker; many participants carefully considered their decision and its implications. Decision-makers from one family who withdrew their offer of donation, were grateful when the treating doctor acknowledged their decision in what the family interpreted as a compassionate and thoughtful manner- which they believed affirmed their decision to decline: *One of the doctors in particular*
was really so humbled. He said it was very selfless and the right thing to do. In the
circumstances it was good to hear (Ian, son of deceased).

The families who had made a decision to decline organ donation and had made their
decisions clear to the treating doctor reported experiences that were consistent with the normal
practices of treatment withdrawal and end of life care practiced in Australian critical care
environments. At a time pre-determined between the doctor and the family, all circulatory and
ventilator support was removed. In most deaths this took place within one to two hours of the
decision. The families that agreed to organ donation had a different experience. Most participants
from families who agreed to donation reported that the next steps in their experiences involved
meeting with the donation staff in the ICU. Consent documentation was then signed and
participants and their families were asked questions about the medical and social history of their
family member. Many participants were unprepared for these requirements and other processes
they encountered after they had agreed to organ donation.

The decision-makers from one family believed that the care their loved one and they had
received over the continuum of death and organ donation had remained focused on the best
interests of their loved one and their family, who were supported with compassion and clear
information. Henry described how the doctor clearly explained each detail of the process: *He*
[the doctor] *was really good* [and] *took us through it step by step. Explained … that organs can’t
be stored, tissue can. Obviously it’s supply and demand; if they needed a heart lung transplant
then they would … So they were really good* (Henry, father of deceased).
Families that formally agreed to donation, by signing consent documentation and meeting with organ donation staff are generally told they can withdraw their agreement up until the time their loved one is actually transferred for donation surgery. This was an important consideration in this study where consent decisions were threatened by the requirement of families to manage new information. Clinical activities required for organ donation for transplantation, such as collecting blood for tissue typing, collating test results and other organ referral information were noticed but not specifically mentioned by the families. Most families commented on the kindness of some staff; however, two families reported a lack of compassion and insensitive organ focused behaviours.

Participant confusion about the role of their family member’s autonomous wish to donate acted as a barrier to the development of trust for some participants that believed the wishes of their loved one were important and should take precedence in the decision-making process. The participants needed reassurance that their loved one’s wishes were foremost in decisions. They expressed frustration and disillusion if health care professionals did not consider, explore or uphold their family member’s wishes. The participants presented ideas that suggested the staff treating the deceased should reassure the family that their loved one and their wishes were important. The staff should also provide information held within registers to the family to help them in their decision-making experience. It became apparent that when the deceased had made a decision that the family knew about, the information appeared to lessen the decision-making burden for the deceased family, regardless of individual family members’ views. Participants were disappointed when they found that previously recorded donation decisions did not appear to influence the decision outcome: *I actually thought that they could over-ride your licence, but if*
you put it on the registry your family couldn’t over-ride it. But since the experience I’ve found out that they can (Linda, sister of deceased).

In conclusion, the sub-theme *This is how it happens* fell within an intrinsically negative theme because it represented the experience all families encountered in their efforts to ‘fit in’ to the needs of the critical care environment in the hope that their family member would recover. It became evident to some families in this study that a power imbalance existed between the needs of their family and the needs of the organisation. This sub-theme encompassed participants experience of 1), bringing the family together for support and decision-making; 2), feeling trapped by the experience and trying to ‘do the right thing’ to fit into hospital environments; and 3), trying to anticipate the health organisations requirements of them, their dying relative and organ donation processes. The theme was drawn from participants whose narratives suggested that on reflection, the deceased organ donation decision-making experience unfurled in a predictable sequence that the families were required to ‘fit into’. Most participants indicated that their families needed information to understand the extent of their relatives’ injuries. Once it became medically obvious that their family members’ condition was not survivable, they wanted a clear understanding of the situation and their choices. This information allowed them to embark on their tasks of preparing for difficult decisions, of honouring their relationships, and preparing for the death. They needed help from their families and health professionals to manage the situation. Once participants realised that nothing more could be done for their loved one, they wanted treatment to cease, perceived suffering to end, and organ donation to honour the deceased. The idea of time and its influence on families’ decisions will now be discussed within the sub-theme *Stop all the clocks.*
4.4.1.2 Sub-theme 1.2: *Stop all the clocks*

*Stop all the clocks* fell within an intrinsically negative theme, *In the fog drowning*, and represented the experience all families encountered involving time and its multiple conceptions. It included first, the idea that ‘time stands still’ for families from the moment they realise that death is inevitable- their world is never the same; second, the idea that time is a ‘bargaining chip’ for negotiation and loss; and third, that time is different for the families caught in the decision-making process compared to ‘others’. The idea that time is an unequal measure was a powerful notion touched on in the narratives of all the participants. The theme represents the decision-makers reflection on the temporality of time and how it influenced the meanings and understandings they attributed to their experiences and decisions. Families in this study were required to reframe their expectations and assumptions regarding their lives, their hopes and their beliefs in the face of new information- this was a time limited situation, and families knew they had to make decisions. This sub-theme was best represented by Jenny when she described her experience that ‘time stood still’ with the death of her child: *Your whole world just stops at that point in time. But you know for everyone else it doesn’t* (Jenny, mother of deceased).

All the participants sought to create an orderly understanding of the sequence of events to enable them to make sense of their circumstances and to understand and anticipate events, responsibilities and decisions. Time was used to remember the family member and the last time they were together. The participants’ understandings of the implications of prolonged time without breathing or oxygen proved powerful delineators of participants’ expectations. Time had great significance for the participants who clearly remembered how long it took for help to arrive. If help was delayed and there were interruptions in instituting treatment, it contributed to
memories of deep frustration: *Then we got a call to say that the [ambulance] flight can’t come, he’s got a broken windscreen. I was devastated, absolutely devastated. I hear that helicopter go over my house so many times. I can identify it, and I just thought I can’t believe this* (Avril, wife of deceased).

The family members described how they were conflicted by their desire to be at the bedside, whilst needing to take time away from the bedside to summon their family: *And I was actually away from the bedside for quite a bit making those phone calls to the embassy and airlines, and all those places* (Nicole, sister of deceased). In some situations death intervened before all the family arrived: *My sister was flying down and wasn’t getting in until 10.30pm. But they disconnected the ventilator; it would have been 7.10pm. My son came but we had to wait for him to fly in and so he only saw ‘Amelia’ [pseudonym] for a bit* (Hannah, mother of deceased).

The idea of spending time in vigil at the bedside was an important element in providing meaning to the participants as they absorbed new information, and tried to reconcile their understandings and hopes for their loved one. The participants spoke of the time used in waiting to find out what they should plan; wondering if the wait was futile, especially if they had been witness to events and had transparent information about the criticality of their family member’s injury. Transparent witness meant that some participants were able to fully understand the severity of the situation, and were conscious that treatment and waiting was possibly futile: *Or give up? You just … it’s just another time line, another set of possibilities that you don’t even want to think about* (Julian, brother of deceased).
Participants used time to measure the prognosis of their loved one. One participant described how she and her family were awaiting the arrival of their loved one following surgery for traumatic brain injury. The participant described how health professionals had set her expectations that the surgery would be prolonged because of the extent of the injury:

*And the neurosurgeon came and said we’re going to take him to theatre. And he said it will probably take four to five hours. So we were there and it was about 90 minutes later they came back to us and said ‘we’re just getting him ready to take back to ICU.’ And I remember my Mum saying that’s a good thing’ and I’m like no, I knew right then that it wasn’t a good thing at all* (Jenny, mother of deceased).

Participants spoke of their anxiety about not having enough time at the bedside, to talk to the doctor or to understand new information. Some participants kept watchful vigil, hoping their loved one would awaken, hoping and praying for a miracle. Most participants did not want their loved one left alone without family, sensing they needed their protective presence: *We kept a vigil* (John, husband of deceased). Brittany described: *She was never on her own. There were always a couple of us in the room with her, and often all of us during the day* (mother of deceased).

Family members used time as a measure to assess the likelihood of their family member’s survival. Participants needed and bargained for sufficient time to come to an understanding of the situation, and to accept the inevitability of death. This version of time appeared to be measured using a different time scale, calibrated by the individual and based on their witness and understandings. The idea of being certain that enough time had elapsed for the family to
understand that everything possible had been done for their loved one was important for participants as they positioned trust. This process required time for the participants to be certain that the situation was hopeless; time for signs of death to be irrefutable, and sufficient understandings of time to recognise the inevitability of death, and the appropriateness of the timing of the request: ‘Annabel’s’ [pseudonym] *not there, she’s gone, you know she hasn’t been there for five days really. You know she was brain dead when she came into the hospital, and we just didn’t want to let her go* (Brittany, mother of deceased).

Time was used by participants as a reference point to frame and analyse the expectations for death and making organ donation decisions ascribed by health professionals. One participant described her understanding of the doctor’s explanation of the role of time in deceased organ donation: *I think it was the timing; it was to do with the timing, [that] if he goes to brain death then we’ll be able to talk about organ donation. So we were half expecting that somewhere in the future, if he went that way, then they’ll talk* (Nicole, sister of deceased). A participant from another family of decision-makers, Linda related the doctors’ explanation of time frames involved for organ donation: *You go and you say your goodbyes. But we’d leave the machines still going, and he’d be left there two or three days* (Linda, sister of deceased).

Time was used to delineate the change between being alive and being dead: *Oh, they timed it. Gave it a precise time. Ten forty in fact. We’ve got a copy of his death certificate in there* (Julian, brother of deceased). Julian knew the time of death was an arbitrary determination that allowed administrative requirements, including organ donation, to proceed. In this participant’s view, the time documented as the time of death bore little relationship to the actual
time his loved one died: *Well, no one knows when ‘Stephen’ [pseudonym] died, or when he would have died. So, essentially,[death’s] got to be given a time for the sake of convenience* (Julian, brother of deceased).

Time for many participants was filled with suffering and seemed interminable, as they came to the realisation that there was no prospect of recovery for the person they knew and loved: *We were just waiting for him to wake up* (Sam, father of deceased). Henry, another father, explained that the time at the bedside was distressing: *I don’t know if I could sit here with him for another two weeks* (father of deceased). Time became an intolerable imposition when participants were asked to wait long periods for organ donation.

*We had made the decision that we needed to switch off life support, but then came the question of organ donation, which to’d and fro’d a bit. Then they came back and said you’re not going to be able to do that [organ donation surgery] until midday tomorrow. We had just lost our Dad. We didn’t want to sit there thinking about whether we were going to donate his organs to someone. Right now, I just wanted to go home and deal with it* (Harry, son of deceased).

The idea of ‘time as a suffering’ factored in declines; especially when participants believed their dying family members were hoping to have their suffering relieved: *It would have been pretty bad knowing that that we’d have to keep him on life support for eighteen hours when he was just itching to go* (Harry, son of deceased). Another participant described how time factored in their decision: *He [daughter’ husband] said ‘I’ve told them no’ and I said ‘I’ve just
told them yes’. He said ‘No, I don't think I could go through another 24 hours’ (Hannah, mother of deceased).

Participants described ideas that suggest health professionals need to carefully analyse the needs of the family before making an organ donation request. The pressure of time and the idea of decoupling events such as understandings of recovery, or understandings of brain death, with requests for organ donation were important in the decision-making process: *It wasn't a long time before they declared her dead and we turned it off, but in that time they called me out to go into the room next door to talk about donating and I felt they were rushing me* (Hannah, mother of deceased).

The reality of the death and the legal and practical requirements of managing the body became part of the experience of delay and confusion for most participants and contributed to their sense of impotence. The practical requirements of viewing and identifying the deceased body and discussing the death with police in coronial cases, as well as trying to plan the next steps of caring for the deceased body and the needs of the grieving family members were discussed by most participants. Most deaths in this study required coronial approval before organ donation could proceed. A participant from a family that had declined organ donation believed that even if the family had agreed, the coroner was likely to have refused to allow the donation to proceed. For families who did agree, the coronial requirements created delays that were particularly noted by the families:

*He [treating doctor] was waiting for the OK from the coroner. The coroner had to give the OK that yes we can turn the machines off. That was a bigger hold up. It got to the*
point the professor at the hospital was ringing every 15 minutes [to speed up the response]. And then they had to get the police to come up and identify [Tim’s pseudonym] body] (Henry, father of deceased).

In another death, according to the participants, administrative inefficiencies contributed to family distress in a coroner’s case. In this situation the family described how they had farewelled their deceased loved one who remained ventilated awaiting organ donation surgery. The family left the hospital to travel home almost an hour away to grieve, and were surprised several hours later when they were asked to return to the hospital to complete formal identification requirements of the deceased with the police. The participants were informed donation would not proceed without their return. The participants described that two family members returned to identify the deceased’ body. The participants claimed the action added to their emotional distress and created an accident risk for the family members. This risk was related to the participants’ fatigue, their consumption of alcohol, and the long distances they drove. The participants believed this issue could have jeopardised the donation if the participants had been unreachable or unable to return. The participants suggested better planning and communication would have avoided the additional distress this family experienced.

Two participants described feeling strongly that if they had been asked about organ donation before concluding that treatment should be withdrawn, they would have been more content to agree to donation. The participants presented ideas that suggest the organ donation question should be sensitively approached and measured against the needs of the individual decision-makers’ understandings and expectations. The participants indicated that it is these
understandings that need to be decoupled: We had the diagnosis of death and the next breath organ donation … We wanted time (Julian, brother of deceased). Hannah made the comment: Had it been talked about [organ donation], not just on the day she was dying, at least it gives you a bit of time to think about it (mother of deceased).

Some decision-makers believed that long distances, remote locations and a lack of resources would delay organ donation surgery and the cessation of treatment- these participants saw time as a barrier to their deep hope to protect their relatives right to a peaceful death: Because of the time. We would have loved to have helped other people. And Dad would have loved to have helped other people (Harry, son of deceased). Jean highlighted that in truth, the donation was impossible from their location: Impossible, a real GI, [geographically impossible situation] (Jean, mother-in-law of deceased). Ivan highlighted that logistical barriers made the time involved in arranging the donation the key reason for the family’s decision to decline:

When it was known that ‘Mark’ [pseudonym] wasn’t going to make it and there were issues so far as timing for the family and the problem of the time it took for ‘Mark’s’ body and organs to be delivered to a suitable donor. That was, as I recall, the main issue as far as this decision not to do it (Ivan, father-in-law of deceased).

Another member from her family described the family’s frustration when they discovered that it could be days before the donation could be arranged:

It was knowing it would take so long. It’s the distance that people have to travel. It’s having $151 million to spend, having it to pay someone, so that they can fly to you within
an hour. Set it aside [the money] and have it to use for teams to travel, to pay them to do it, so they can fly that in an hour (Harry, son of deceased).

Conversely, the idea of planning time so that there was sufficient time for the family to properly farewell their loved one in the context of the organ donation decision, was important to several families that agreed to donation in this study. Some participants from these families suggested that families are fearful of an early separation from their family member’s body, because they have not had time to imagine or plan for the separation. They argue that this difficulty may influence families to decline donation. An example of this construction of time and its influence in the decision-making process of organ donation is represented in this conversation between three participants explaining their anxiety when leaving their family member’s body following the death. The participants’ suggested that the barrier to organ donation may not be the actual surgical process but rather, the family need for sufficient time to anticipate and plan to separate from their family member’s body when either transferred to the operating theatre, or when leaving the hospital: They haven’t pictured letting go in advance, and that’s something that you need to be able to do. I think you need to be able to visualise it in advance (Ruth, mother of deceased).

They just want to be with them, they don’t want them to leave that hospital; they don’t want them to leave (Nicole, sister of deceased).

You need time. You need to have time (Suzanne, sister of deceased).

But it was not knowing how much time we had to have him to be able to hand him over, you know, that was the thing that I didn’t know, and I hadn’t processed it beforehand (Ruth, mother of deceased).
The idea that organ donation may delay funerals was revealed in one family’s narrative. It is often stated by OPO’s that organ donation will not delay funerals; however, some participants in this study were of the view that if they had agreed to donation, the funeral would have been delayed; and that this was a disincentive to organ donation. Participants from several families thought waiting another day for organ donation processes was an unreasonable delay for families who were trying to find ways to survive in their changed situation: *Look 24 hours would have been impossible under the circumstances. We’d had a private funeral within two days, with just the family here* (Jean, mother-in-law of deceased).

In conclusion, *Stop all the clocks* fell within an intrinsically negative theme, *In the fog drowning*, and represented the experience all families encountered involving time and its multiple conceptions regardless of the context of death and DCD or DBD decisions. The sub-theme encompassed the ideas that 1) ‘time stands still’ for families, from the moment they realise that death is inevitable, their world is never the same; 2) time is a’ bargaining chip’; and 3) time is different for families caught in the decision-making process compared to ‘others’. Families in this study were required to reframe their expectations and assumptions regarding their lives, their hopes and their beliefs in the face of multiple new information- this was a time limited situation, and families knew they had to make a decision. Participants spoke of time regretted in the context of both past events, future guilt and unforgiving time with memories. The participants spoke about their need for time to think and to grieve. Perceptions of time were crucial to the family deceased organ donation decision-making process in this study. Fear of prolonged suffering and delays in the provision of information were a barrier to consent in this study.
4.4.2 Theme Two: It’s all up to Mum

The second major theme represented in this study, It’s all up to Mum and its two sub-themes, Well you never give up hope and Trust protected are diagrammatically represented in Figure 4.11.

Figure 4.11 Theme 2. It’s all up to Mum and its sub-themes.

The major theme, It’s all up to Mum and its two sub-themes, Well you never give up hope and Trust protected, are intrinsically positive themes are associated with the power of families to make decisions that reflect their needs and the needs of others. This overarching theme particularly highlights the influence of women as decision-makers. The idea that ‘mothers’ hope for and protect their family members feature within this theme and its two sub-themes. The theme was bounded by the crisis event that caused the critical injury, the recognition that death was inevitable, the diagnosis of death, the organ donation decision and its consequences. The key findings within this theme include first, mothers were key influencers of donation decisions; second, the mother or ‘mother figure’ played a pivotal role as family ‘protector; and third, the
mother is the carrier of family memories and wishes. The name of this theme is drawn from a comment made by Linda who described that her mother had provided the final say in her family’s organ donation decision: *It’s all up to Mum* (Linda, sister of deceased). Linda argued the family would support the mother’s views because of their fear of ongoing suffering that the mother and family would endure if the mother believed her child suffered as a consequence of a decision to donate. Linda believed this view was appropriate in the context of the mother’s protective relationship with their child, even if the ‘child’ was an adult: *Because at the end of the day it really did come down to Mum. I wouldn’t and Dad wouldn’t fight with Mum, we’re a family. It comes down that a mother is closest to her kids really and they’re a part of her* (Linda, sister of deceased).

This theme represents the finding that a mother was the key influencer in the decision-making process of all consent decisions in this study. It also represents the finding that eight of the deceased organ donation decisions appeared to be directly influenced and decided upon by mothers of the deceased, other women ‘mother figures’, or their representatives. The families’ deceased organ donation decision was presented to the treating doctor in most cases by either the mother of the dying/deceased patient or by her representative.

One participant described how his partner, the mother of the dying patient, broached the idea of donating their family member’s organs:

*Jen looked across at me and said ‘imagine if the doctors walked in here now and said we can give ‘Tim’ [pseudonym] a new head and you can take him home. Imagine what we’d*
feel like?’ I said ‘yeah you’re right, well, where are you going with this?’ … She said, ‘well what about donating his organs?’ (Henry, father of deceased).

In the two deceased organ donation decisions in which family members were asked to agree to organ donation by emergency department doctors, the requests to donate were made to the mothers of the dying family members. Each of these requests was initially agreed to by these mothers. In one decision the request was made while the parents were together in the emergency department, just after the doctor had explained the critical nature of their family member’s injuries and explained that he was unlikely to survive. Ruth, the mother of the dying patient, remembers her response when asked about organ donation: ‘Did you realise that ‘Hamish’s’ [pseudonym] registered as an organ donor?’ … And I said, ‘Yes, we know that.’ And he said, ‘Are you alright with that?’ And we went, ‘Yes, we’re right with that’ (Ruth, mother of deceased).

The second family experience of making a deceased organ donation decision within the setting of the emergency department was also narrated by the mother of the dying patient. This participant had agreed to organ donation while speaking by telephone with the emergency doctor who was treating her son. According to the participant, a doctor at a distant location called late at night to inform her that her son was critically injured and having tests. The doctor called again a short time later to confirm the dire prognosis, and to ask about organ donation:

She said, look we’re going to go and do a CT scan and we’ll ring you back.

So she rang back half an hour later and said, ‘it’s not good’.
And then she [the doctor] went, ‘oh…ah ...um’ and I said, ‘you’re going to ask about organ donation aren’t you?’ And she went, ‘yes’. So we were asked the question (Louise, mother of deceased).

Louise agreed to organ donation at this point in time, but asked to see her son first.

In the four decisions in this study in which the doctor that had been treating the dying patient declared the patient brain dead, and then asked the decision-makers for their agreement for deceased organ donation, two families agreed to deceased organ donation and two families declined. In one of the consent decisions following the declaration of brain death, the mother of the deceased and her husband were told of their daughter’s death and shortly afterwards were asked to donate her organs. Brittany describes her response: Our immediate response was yes, because we knew that’s what ‘Annabel’ [pseudonym] would want, because she was a really generous kid. She’d always worried about people who looked like they needed help ... It’s exactly what she would have wanted to do (Brittany, mother of deceased).

In the second decision to agree to organ donation was made after the treating doctor had told the family their relative was brain dead. The decision was discussed within the family and confirmed by the mother of the deceased. The decision was presented to the treating doctor by the mothers’ representative who explained: It was her decision. I mean, obviously... As a mother (Julian, brother of deceased). In eight deceased organ donation decision-making cases ‘mothers’ or ‘mothers’ representatives’ described how, after communicating the decision to the health professionals, the decision-makers and particularly the mothers, actively sought out information to understand the implications of their decision.
In conclusion, the major theme *It’s all up to Mum* and its two sub-themes, *Well you never give up hope* and *Trust protected*, are intrinsically positive themes associated with the empowerment of families to make decisions that reflect their needs and the needs of others, despite being situated within the context of unexpected death that underpinned all participants’ experiences in this study. This overarching theme particularly highlights the influence of women as decision-makers. The key findings within this theme included 1) mothers were key influencers of donation decisions; 2) the mother or ‘mother figure’ played a pivotal role as family ‘protector’; and 3) the mother was the carrier of family wishes and memories. A mother was the key influencer in the decision-making process of all consent decisions in this study. The motivation and affirmation of the decision to donate will now be presented in the sub-themes *Well you never give up hope* and *Trust protected*.

4.4.2.1 Sub-theme 2.1: *Well you never give up hope*

The sub-theme, *Well you never give up hope* falls within the intrinsically positive theme of *It’s all up to Mum* that was associated with the power of families to make decisions that reflect their needs and the needs of others. There was clear evidence within this theme that families who had their hope needs met were more inclined to agree to organ donation. This sub-theme encompassed the participants’ experiences of hoping for their families. The participants’ narratives revealed the progression of hope as they traversed the situation. First, the participants hoped for a miracle; second, they hoped that their loved one was not suffering; and third, they hoped to keep their family together and to never forget good memories of the meaning of their family members’ life. This became a deep hope that sustained the families long after the events. The name of this theme is drawn from a comment made by two participants describing how hope
Hope and deep hope appear to have directly influenced decisions to either offer deceased organ donation or to consent to a request for deceased organ donation in this study. In each decision to offer or accept deceased organ donation of a dying or deceased loved one, the participants discussed how their hope to find meaning from the death, and desire to honour their family member’s wishes influenced their decisions. Many participants presented the idea that they hoped to save lives and protect other families from the grief they were experiencing. The participants’ use of hope and its meanings appeared to be context dependent. The decision-makers continuously re-evaluated their initial ideas about the hope for recovery of their family member, in the light of their witness of clinical events and new information; whereupon they refashioned their hopes.

Hope carried a range of meanings and was strongly represented in the participants’ descriptions of their decision-making processes. Hope was revealed in both the attitudes of the decision-makers towards their family member’s survival, and in their efforts to secure their family member’s memory and honour their identity after death. Hope was balanced in the understandings of decision-makers across the continuum of the decision-making process. It began with learning of the critical illness, comprehending the evidence of dying, and acknowledging the ‘hopelessness’ of continuing to anticipate their family member’s recovery; before reframing the idea of hope for recovery into other hope goals for the future. The earlier the decision-makers were able to conceptualise the inevitability of death and the hopelessness of...
thinking about recovery, the earlier they were able to engage with the decision-making processes of deceased organ donation: *There was never any indication given that there was any hope, so from the time we got there it was just down this path* (Louise, mother of deceased).

The participants described their relief when help arrived and when health professionals were able to institute treatment that provided them with hope for their family members’ survival. John described how the provision of treatment provided him reason to hope for his wife: *I think every time they did something there was always hope, there was something* (John, husband of deceased).

Ideas of hope and trust were presented by these decision-makers and they appeared to balance hope by testing the new information from health professionals for truthfulness, and by seeking ways to sustain deep hope: *And you feel like that’s your role as a mother, to hang onto the last little bit of hope. Like who else is going to fight for your child if you don’t?* (Ruth, mother of deceased).

Any initial hopes for their family member’s survival were proven to be misplaced as the events unfolded for the participants in this study. The idea of ‘misplaced’ hope and the role of a miracle could be interpreted as denial in the experience of some participants who were initially disbelieving of the information they received from health professionals regarding their family member’s condition: *We were actually hoping for a miracle … like recovery. We were hoping that they were wrong* (Suzanne, sister of deceased).
It appeared that the participants used this form of hope to assist them in adjusting to the new and distressing information about their family member’s critical condition before accepting its implications. The idea of hoping or praying for a miracle influenced the decision-makers’ conceptions of the hopelessness of the situation and their view there may still be hope of recovery for their dying family member. Decision-makers described the role of their religious faith and in their conceptions of hope in their decision-making experience. For example, Hannah provided a narrative in which hope is refashioned from a hope for her daughter’s survival, to a deep hope she would not suffer by surviving in a brain-injured state:

Well, as my husband said, you never give up hope. My sister and my mother were very religious and I also go to church; and we prayed that there would be a miracle until the end. I think that at the end I felt that if she was going to be brain damaged then I didn't want her to live, because they are the worst deaths (Hannah, mother of deceased).

During this period family members described how, despite having information presented to them about the dire circumstances of their family member’s condition, they drew from stories of unexpected recovery and medical mistakes to retain hope of a mistaken diagnosis. Misplaced hope became apparent in four deaths where participants described the hope expressed by either themselves or others in ‘hoping for a miracle’; and in five deaths wherein participants ‘hoped the doctor was wrong’. These ideas were held by both donor and non-donor families: Maybe in my heart I knew that it didn’t look good from the start but you still had that hope. You hear so many stories where people have been written off but have come through (Hannah, mother of deceased).
Having accepted the futility of continuing to hope for recovery the participants fashioned new ideas of hope including ideas about hoping their loved one was not ‘a vegetable’—a prospect viewed by most participants as a fate worse than death—and hopes for their loved one to have a peaceful death:

*He had no chance of recovering to the person he was, he would not at all be the person he was and that he would be, a vegetable* (Ian, brother of deceased).

*Or the belief that while there’s life there’s hope for a recovery … Except that it’s not life, you know* (Brittany, mother of deceased).

*He’ll never be ‘Hamish’ [pseudonym] again* (Ruth).

Some participants presented accounts about how visual and physical access to their loved one in the critical care environment provided them with a realistic view of the situation. The ability to understand the irreversibility of the condition subsequently influenced the participants’ decision-making process, and allowed them to refashion their hopes for the future: *And there was this assumption that she was brain dead at that point and she looked pretty terrible* (Joelle, aunt of deceased).

The decision-makers that agreed to organ donation in this study needed to know that there was no hope of meaningful recovery for their loved one before being satisfied. Most families who were accepting that nothing else could be done responded with either a decision to offer donation or agree to donate: *He came back to us and said, as we expected, that the tests now showed conclusively that she was brain dead, and there was no hope of resuscitation* (Christophe, father of deceased). A participant from another family described how her spouse
related the news of their family member’s critical condition, and emphasised the absence of hope: *You rang me and just said, ‘No, there’s no hope’* (Sarah, sister of deceased).

The idea of hope was expressed by Jenny and Henry as being able to find meaning from the death of their son. In two deaths, this idea influenced the decision-makers to offer organ donation to the treating doctor before the question had been posed by health professionals. Jenny, a mother, was motivated by the hope that organ donation could save another family from a similar experience of grief:

*She said, because we have the ability to give that miracle to another family. And I said yeah you’re right we do. We called the ICU doctor and said look this is what we’re thinking of, can you find out whether he’s eligible to donate his organs?* (Henry, father of deceased).

The idea of hope and how it evolved over time was described by Avril who offered organ donation after concluding that her loved one’s death was inevitable. Avril explained that she saw and understood the extent of her loved one’s injuries and knew they were un-survivable. She and her family had gathered at the hospital and had spent time at her husband’s bedside before meeting with the health professionals that were caring for him. Avril described seeing her husband just before her discussions with the treating doctors, and feeling deeply distressed by his deteriorating condition and her observations of suffering:

*His head was hot, hot, hot. And his hands were cold and his heart rate was incredibly high. The breathing was being done for him, he was starting to get these big bruises under his eyes and I was told that there was so much bleeding it’s got nowhere else to go.*
That the crack in his skull had released a certain amount of pressure but it couldn’t take any more so it’s starting to come through here. That was really so traumatic. He looked really, really uncomfortable, even though I know he wasn’t with it (Avril, wife of deceased).

Avril explained that during her meeting with the doctors and nurses it became clear that her relative could not survive. She was therefore shocked and surprised when at the same time as feeling overwhelming despair; she suddenly found a sense of hope and meaning emerging from her grief. This was experienced at the same time as she imagined a recipient’s life being saved by the donation of her husband’s organs: It was like this lightness … maybe I’ll meet the young boy who got his heart … it gave me such a feeling of lightness after such incredibly sad feelings … it was like being on a roller coaster with only one up (Avril, wife of deceased).

Avril described her subsequent feeling of despair when she realised that time as a barrier would preclude her family from being able to agree to the donation: it then came crashing back down (Avril, wife of deceased). Her decision to decline donation was based on her deep hope to protect her husband and family from prolonged suffering to enable a peaceful death.

Once the participants had accepted the hopelessness of the prognosis for their family member, they started to speak about ideas of hopes for their family member’s memory. These ideas encompassed their deep hope that their loved one was at peace, with their identity protected and remembered well. These changing notions and conceptions of hope happened over time and required transparent information and compassionate support from the health care professionals.
involved in the care of the dying patient, to help the decision-makers understand the meaning of unfolding clinical events and to enable the decision-makers to construct new hopes and support deep hope.

The wishes of the deceased were known to most decision-makers through written documentation and remembered discussions:

*I guess once we knew that ‘Hamish’ [pseudonym] was going to die, that we were then holding onto the hope that he could donate. Because I remember us saying, ‘It’s what ‘Hamish’ would have wanted, at least if he’s gone some good will come of it, that’s what ‘Hamish’ wants,’ and it [refusing] just never really was an option* (Ruth, mother of deceased).

‘Kieran’ [pseudonym] blew in like he used to do, and had his head in the fridge. And I said ‘look mate if it happened to you, what would you want us to do’, and he stuck his head out and said, ‘well if I’m dead they’re no fuckin’ good to me’, shut the fridge and walked out (Louise, mother of deceased).

The participants’ ideas about their deep hope to honour their ‘contract’ with the deceased, their family member’s wishes and to create a positive outcome from their tragedy were found to be the primary motivators for the decision-makers that agreed to deceased organ donation. In one death, the decision-makers were unsure about their family member’s views, and drew from their hope to benefit others when making the decision: *It probably helped to make the decision, in a way you know, let’s get something good out of something bad* (Julian, brother of deceased).
The deep hope for family unity and a peaceful death was strongly represented by the participants as part of their decision-making processes with the idea that the deceased and family were ‘as one’: *So we sort of talked ourselves around and the fear at that point was very much that we would end up at loggerheads with each other. Everyone just agreed that that’s what we would do … we went forward then* (Brittany, mother of deceased).

Efforts to negotiate a dignified and peaceful death and create rituals for a good memory of the deceased fell within this theme as the family members sought to protect the memory of their family member. One participant spoke passionately about the benefits that agreeing to organ donation had provided him and his family, believing the decision had provided his family with continuing permission to talk about their family member in everyday conversation and kept their family member’s memory alive. This same participant compared his experience of grief to the experience of other bereaved whom he had heard acquaintances speak about in a negative way because they continued to speak about their deceased relatives beyond an ascribed acceptable period of ‘grieving’. He presented the idea that community affirmation of saving of life through organ donation gave him permission to speak about his son without being judged as grieving inappropriately: *And yeah, you’re able to talk about him without people going ‘oh geez it’s been seven months and they’re still talking about their dead son’* (Henry, father of deceased).

When the decision-makers were able to structure rituals around their ideas of a peaceful death, they appeared more content with their experiences and described less regret for their decisions. The participants that described a sense of being in control of the moments of
separation from their family member’s body appeared able to reflect on ‘good’ memories of saying goodbye and appeared to have a better view of their experiences than other participants.

Decision-makers from four families described the processes they used to ensure a peaceful death and to gain a sense of being in control of saying goodbye to their loved one. Two of these deaths involved consent decisions that were dependent on the family’s ability to achieve their deep hopes of a peaceful death and family unity beyond death. Following the donation of their loved one’s organs the participants from one family described the importance of being able to touch and hold their son for one last time before being separated permanently from his body. They spoke of how health professionals helped them by lifting and positioning him for them to hold, and by offering to take photographs to record the moments of saying goodbye. These actions helped the participants affirm their hopes for tangible memories of their son: And yeah they were very respectful. Obviously being dead weight they helped, you know … they took some photos for us so we had them (Henry, father of deceased).

All families that believed their family member’s body and life meaning had been cared for and respected by the nurses and doctors at the bedside expressed satisfaction that everything possible had been done to care for their relative, regardless if the deceased became an organ donor: I met the doc, and he took me in and she looked … beautiful (John, husband of deceased).

The special meaning ascribed to the heart was clearly evident in the reflections of seven participants from five different families, in which the idea of hope for the survival of the heart and recipient was discussed: That maybe one day I’ll meet the young boy who got his heart
(Avril, wife of deceased). The participants that had agreed to donation pinned deep hope to the outcomes of the heart donation, with three decision-makers specifically commenting on the use of the heart, which although offered was not used: *And that they hadn’t taken his heart …* (Louise, mother of deceased); *And it was then that it actually hit me that they couldn’t use his heart. I had like a complete meltdown* (Jenny, mother of deceased). Whereas, the decision-makers that were informed the heart was used and were told the outcomes of donation were particularly satisfied with that knowledge: *They told us on that day, at the funeral they said that a girl about the same age as Annabel got her heart immediately, and they said she would have died by the weekend if she didn’t get it* (Brittany, mother of deceased).

Hannah described how she believed the hope of being able to meet recipients could benefit future decision-makers to agree to organ donation. She believed it could enable some donor families to find meaning from their donation. Hannah illustrated her meaning with an anecdote of a donor family member and heart recipient interaction:

*She can rest her head on the other person's chest and hear her brother's heartbeat, and that makes her feel good. Apparently the family is a really nice family so it's gone to a good home. That's made her feel good that her brother has helped someone* (Hannah, mother of deceased).

One participant spoke about how a relative had benefited from organ transplantation from a deceased donor and how as a result of this knowledge the family had ensured they had all ticked boxes on registration forms to donate: *My uncle was the recipient of a kidney, he’s just*
passed away, he had kidney disease for many years, and he finally got a kidney and I’ve been a firm believer in it (Avril, wife of deceased).

The age and health of the donor was considered by some participants as they imagined the benefits their loved one’s donation could bring to others, rather than being ‘wasted’:

You know to lose someone like her, so healthy, and never been sick, on the brink of growing up. It’s such a waste to suddenly just be snuffed out like that, and to know that she’s made a difference to six or seven other people doesn’t make it better, but it just makes it not such a huge waste. It’s a really good thing to think of (Brittany, mother of deceased).

The ideas of hope extended to the decision-makers’ plans for what needed to happen next to care for their family member’s body and family. The idea of being able to reflect on the experience and feel content with the outcomes was important; as suggested by this participant that reflected on the deep hope outcomes of the organ donation decision made on behalf of her daughter: Yes, this is what she would have wanted (Brittany, mother of deceased).

Three participants spoke of their family member and ideas related to their hopes and understandings of a sense of immortality, or describing a sense that the deceased family member had visited or been present with the decision-maker in the hours, days and beyond following the death, a feeling that provided comfort to the participants that reported this meaning and appeared to contribute to their sense of deep hope: There was just this … something. And I knew that they
were being looked after … And whether people believe that’s true or not doesn’t matter because I believe it’s true (Linda, sister of deceased).

The families that agreed to donation have had a range of follow up and acknowledgement regarding their organ donation decisions, with three participants indicating they were generally satisfied with the acknowledgement. However, one family was disappointed by what they perceived as poor follow up and acknowledgement. The four families whose family members ultimately donated were provided with de-identified outcomes of donation and most received telephone follow up from the organ donation organisation. Participants that agreed to organ donation in the hope that it could save the lives of others were generally satisfied with the outcomes of their decisions and the hopes that were represented in the lives of the recipients for three of the four families whose family member donated organs:

What you want to know is that someone else got a chance. I don’t need to know any more than that (Christophe).

She’d received letters from the different girls that had received the parts, the organs. And their thanks and gratitude, which was absolutely wonderful (Julian, brother of deceased).

The experience of making an organ donation decision has brought new insights and understandings about organ donation to the families that were interviewed in this study. Most participants believed that they made the best decision they could under the circumstances:

I think that he would have been all for donating but I might have been wrong. I think he would have been pretty happy with what we came up with in the end (Ian, son of deceased, non-donor).
Well, through our loss, it was a great loss. A hand full of other people got an opportunity, another chance (Julian, brother of deceased, donor).

However, most of the decision-makers reflected that their decision to donate had required some sacrifice for their family as they encountered the organ donation process. These organisational requirements contributed to an undermining of their hopes for organ donation and led to a greater awareness that their donation was in fact a gift of their family member’s organs from both their family member and themselves. The finding that families were driven by deep hope to continue with the donation process despite their reservations; or strove to protect their family and family member’s life meaning and memory despite their known wish to donate, is indicative of the way deep hope played a major role in deceased organ donation decisions. When hopes were lost, or found to be false, organ donation decision-making was undermined; decision-makers evinced signs of despair, and organ donation less likely to proceed as families sought to protect their family member. When trust was protected, deep hope and consent to organ donation flourished.

In conclusion, the sub-theme, Well you never give up hope rests within the intrinsically positive theme, It’s all up to Mum that was associated with the power of families to make decisions that reflected their needs and the needs of others. There was clear evidence within this theme that families who had their deep hope needs met were more inclined to agree to organ donation. The participants’ narratives revealed the progression of hope as they traversed the situation commencing with, 1) hope for a miracle; 2) hope that their loved one was not suffering; and 3) deep hope to keep their family together and their loved one remembered well. Deep hope appears to have directly influenced decisions to either offer deceased organ donation or to consent to a request for deceased organ donation in this study. In each decision to offer or accept
deceased organ donation of a dying or deceased family member, the participants discussed how their desire to honour their family member’s wishes and their hope to find meaning from the death influenced their decisions; however, the deep hope for the protection of the deceased from any perceived suffering, and family survival over-rode consent to donation. The balance of trust and its role in decision-making will now be presented in the sub-theme *Trust protected*.

4.4.2.2 Sub-theme 2.2: *Trust protected*

The sub-theme *Trust protected* encompassed all participants’ ideas regarding their needs for first, compassion, protection and dignity for the deceased; second, respect for the life meaning and wishes of the deceased; and third, reciprocity and acknowledgement regarding the experience. The participants all described their responses to the threat to their family member’s life with ideas that encompassed the decision-maker’s own need to survive, to fight for and to defend their family unit; and importantly, to protect their dying family member and their families’ interests. This sub-theme identifies the significant role that trust played for participants who needed to be assured that there was no conflict of interest in the treatment provided to their dying family member, or in the relationships between themselves as decision-makers and the doctors and nurses. The name of the theme, *Trust protected* represents the experience of participants who had their deceased organ donation expectations met and perceived that their family member was valued: *They worked constantly; they didn’t want to leave him. I’m so happy we donated his organs* (Jenny, mother of deceased).

The idea of early and trustworthy information coupled with proactive care for the participants and their family influenced the formation of trust of the families that offered organ
donation. One offer of donation was made after the decision-makers recounted an experience of exemplary care in that the family believed that everything possible had been done to care for their son and their family. Henry (father of deceased), explained that the care commenced prior to his arrival at the hospital. Shortly after the critical injury, while the family were still travelling to the hospital, the parents were contacted by the hospital and updated about their son’s condition:

*We got a phone call from either the nurse manager or the nurse in charge of ED. But she rang us on the way down saying ‘look he’s just arrived’* (Henry, father of deceased).

*And he’s alive* (Jenny, mother of deceased).

*And he’s alive. And I remember looking over the back seat going ‘Jen he’s still alive!’* (Henry, father of deceased).

These participants described how their family received support and assistance from the moment they arrived in the hospital to enable them to gather in dignity and privacy within the hospital and with proximity to their son. These decision-makers described how they and the health team worked in partnership to care for the family member before and after organ donation had been agreed upon. This level of support was maintained for this family throughout the entire period of the hospitalisation and following the planned withdrawal of treatment, confirmation of death, organ donation process and ongoing relationship with the organ donation organisation. The participants described how they valued the compassion they felt from the staff and the support they received to be with and witness the care for their son. The flow of consistent and transparent information they received from doctors and nurses protected their trust and was
deeply appreciated. This was an important observation and was unlike the views held by almost all the other participants in this study.

The idea of honesty in the information given by the health professionals was important for the formation of trust by the participants that described how they needed to know and understand what was happening to their family member, and depended on the doctors for this information. Harry describes how clear information and communication was valued:

*The thing I appreciated was the fact that they were brutally honest right from the start not beating around the bush, but just sort of putting you in a better position. As soon as we got there we knew all about it, which made it a lot easier to deal with. I appreciated that, and I was pretty happy with the way that we were dealt with* (Harry, son of deceased).

Early actions by health professionals to create positive relationships appear to have helped foster trust in the deaths where the families were able to have access to their family member to see for themselves what was happening. In two deaths the participants described how they were initially worried that the treating doctors in the regional centres may not have been equipped to give competent treatment because of limited health care resources in regional locations: *Other parents that I’ve spoken to that have been in the same situation say, ‘You’ve just got to trust the doctors,’ and I go, ‘Well I come from a country hospital and I know that (laughs), you know, probably five out of ten times … they’re struggling too.’ It’s just they don’t have those skills* (Ruth, mother of deceased).
Some decision-makers valued the role of emergency nurses in helping the families gain proximity to their family member in the emergency departments; describing how the nurses guided the family members as they tried to touch and communicate with their family member. These and similar caring actions appeared to contribute to the development of trust for the participants by affirming their family member was receiving adequate care. Louise described the nurses in a regional emergency department: *The nurses were exceptionally good there* (Louise, mother of deceased). Lucy described how the nurse engaged with family members and helped them to understand the treatment and interact with their family member: *And she encouraged us to talk to him, and said you know, we don’t really know what they can hear or can’t hear* (Lucy, sister of deceased).

Jenny spoke about how she valued the nurses who listened to her stories about her son:

*You know, when you’re sitting there I remember saying to a couple of them, this is ‘Tim’ [pseudonym] and I’m showing them the photos and you know they wanted to see what he was like, and to even listen to you tell your silly little stories about him. I honestly think that helped because it didn’t come across as, oh we give his organs and that’s it.* (Jenny, mother of deceased).

When doctors involved in caring for the family member provided the decision-makers with the option of continuing to treat and clinically support their family member over a longer time frame, with the purpose of assuring the family that the diagnosis was indisputable, the participants appeared more trusting in the diagnosis, and more satisfied their needs were addressed: *I do remember them saying, you can keep him alive for another 24 hours just so you...*
can see we’ve done everything we can, even though we can't see the outcome changing (Harry, son of deceased).

So that was reassuring, to know that everything possible had been done and tried

(Brittany, mother of deceased).

The declaration of death was made in all but one case by a treating intensive care doctor. When a request to donate was made in the ICU it was made by the treating intensive care clinician. The responses to the request for donation were often directly related to information provided by the doctor and the trust that the family had formed in the care, and in their relationships with the doctor. The families reported a range of relationships with the doctors that cared for their family members. It must be noted that the individual doctors would have changed shifts in some of the cases, but overall, because the time frames were limited for most of these patients, there were generally only one or two doctors mentioned in each case. The participants valued kindness and acknowledgement from nursing staff and doctors:

I was very thankful that I had, a professor … he was so beautiful. A gentle, quietly spoken nice man and actually said to us something like ‘In the circumstances you're being very generous [about] our handling of it.’ We weren’t blaming anyone, he was lovely and I’m thankful we had him. Even the girls, they were so kind (Hannah, mother of deceased).

Participants from three families described how they actively sought information to inform their options about organ donation before either offering to donate or when anticipating they would be asked to donate. In earlier discussion the role of nurses was mentioned and their influence was evident throughout the themes. The participants described how decision-makers
first discussed the idea between themselves and then with nursing staff at the bedside, and finally the decision-makers either offered donation or sought further information from the treating physician. The nurses were described by the participants as playing roles as carers of the family member, explainers of technology, clarifiers of information and go-betweens in communication between the family and the doctor: *The nurses were exceptionally good there* (Louise, mother of deceased). According to the participants nurses were to be trusted at the bedside; however, that trust was undermined if circumstances revealed that a nurse was unable to manage the situation through inexperience. Fear that their family member may be suffering and a desire to protect them from suffering was a significant factor in participants’ conceptions of trust in the care being delivered to their family member: *I asked, can you promise me that he is not feeling anything; can you really promise me that?* (Avril, wife of deceased).

It was important for the decision-makers that agreed to organ donation to be assured that there was no conflict between the needs and interests of their dying family members, and the possible needs of recipients or health professionals that represented recipient interests. Interestingly, the participants that felt there was no conflict of interest in their experience and those that were concerned about the possibility of a conflict of interest all raised the topic in their narratives about their decision-making experience. A participant that agreed to organ donation after brain death explained why the timing of the request for organ donation was important to the families’ ability to trust. She argued that it was important to know that death was inevitable:

*I mean I wouldn’t have wanted to be asked about organ donation the first day. Like, if there’s no hope do you want organ donation? I mean I’d be worrying that they hadn’t … So it wasn’t until there was no choice* (Brittany, mother of deceased).
Avril described how her family valued the support of the doctors and nurses that provided them with information that they perceived as trustworthy and value-neutral to assist them in deciding about their options for the withdrawal of life-sustaining treatment and organ donation:

*We had two doctors and a nurse in there telling us about what had happened and what possibilities we had to deal with it. I think we all really trusted and valued their opinions, and they were really good at remaining [separate] that it was our decision not theirs* (Avril, wife of deceased).

One family of decision-makers faced with an organ donation decision following the confirmation of brain death described how they viewed the relationships and decision options available to them as transparent, and respected the staff for their efforts to eliminate any perception of conflict of interest between the needs of their family member and the needs of those awaiting transplantation when describing how the treating doctor had actively sought to remove any idea of conflict of interest by addressing the issue directly:

*The team’s got nothing to do with the hospital, they’re coming from [major hospital],’ and he said, ‘and the organs won’t be used in this hospital’. We understood that there was no other agenda; you know that they needed a heart, or they needed a liver in that hospital or anything like that* (Christophe, father of deceased).

In five of the deaths, donation doctors and nurses were involved in discussions with families about the donation decision. These deaths comprised four deaths in which donation proceeded and one death where the decision-makers declined donation. There appeared to be a significant variation in the quality of the relationship between the families and the donation staff.
and the part they played in the organ donation experience of these families; and this influenced
the development of trust between the families and the professionals, particularly if families
believed information was being withheld. Two families reported the donation professionals were
able to assist them with additional information about the requirements for organ donation, which
clarified the processes of organ donation for the families and assured them that they were
informed. In these deaths the decision-makers received new information that helped them to gain
a better understanding of what the decision entailed: *Then they brought a lovely little girl who
was the actual coordinator, she was really sweet. She explained things* (Hannah, mother of
deceased).

Decision-makers looked to the doctors for compassion, consistent information and
honesty. Some participants reflected that they established a better rapport with one doctor over
another, but all provided ideas about how they depended upon their professionalism: *There are
some doctors … some people you have a direct animosity to, probably the way they talk* (John,
husband of deceased). Harry reflected: *Sometimes I’m too trusting, but in that situation they’re
not going to tell me something that’s not true* (son of deceased). Ruth describes the trusting
relationship she established with the emergency doctor who initially asked told her about her
sons’ devastating and un-survivable injury, who then raised the question of organ donation, to
which she agreed: *I guess that stuck in my mind right from the start … very clearly with that
young nice doctor at the start, and his way of telling us was actually really good* (Ruth, mother
of deceased). Ruth and the other participants from her family compared that relationship to the
relationship they formed with the doctor who subsequently assumed care for their family
member in the ICU. Nicole, another family member, describes the difficulty she and her family experienced in developing a rapport with this doctor:

_The two bad things that I can take out of it, that I could say that could have been changed was the intensivist’s abrupt and snarky manner he had when he was telling us the medical facts_ (Nicole, sister of deceased).

_It was like we were really taking up his time. He had quite a bad bedside manner_ (Ruth, mother of deceased).

There was a sense of confusion for some decision-makers about what constitutes death, and specifically brain death and how it applied to their family member’s condition. However, the theme of trust overrode these concerns as described previously by one participant that had agreed to organ donation, then declined, until finally agreeing to accept on trust the information provided to them about death: _See then you come down to that argument about what constitutes life, what’s the point of death? And one thing that we said to each other that night was we weren’t going to have that argument_ (Brittan, mother of deceased).

Participants’ reflections on the donation experience revealed the importance of clear information and support throughout every step in the experience. In one consent-to-organ-donation experience, the dying patient was not yet brain dead. However, continuing life-sustaining technologies was thought to be futile. Therefore life-sustaining treatment was withdrawn when the family and the organ retrieval team were ready, in a planned DCD: _They turned all the machines off and we were holding his hand and they took the tube out and he_
didn’t even take a breath … He’d finally admitted that no, that was it (Henry, father of deceased).

Clear and supported information helped to affirm family decisions despite the requirement that the body of the deceased had to be transferred to the operating theatre for organ donation surgery almost immediately following the declaration of death. The participants spoke about their appreciation of knowing their family member’s body had been cared for and returned to them in a dignified way following the donation surgery. The idea of compassionate person- and family-centred care was described by this participant, who relates his memory of having the body of his family member returned to the family for viewing: *The actual recovery and the post stuff was very compassionate … They’d dressed him as best they could and they’d bathed him. We got to spend fifteen, twenty minutes* (Henry, father of deceased). These caring strategies contributed to the overall trust the family felt in the care that was provided to their family member and affirmed their decision to donate. Jenny describes the ongoing meaning that their family was able to find in their organ donation decision: *They worked constantly; they didn’t want to leave him. I’m so happy we donated his organs* (Jenny, mother of deceased).

The nurse’s role as carer and protector of the family member’s body appears to have been highly valued and some participants spoke about being grateful they could entrust their family member’s body to the nurses at death and following death. In one death the nurse was asked by the family to stay with their family member after the removal of life-sustaining technology, and in another death the nurse offered to stay with the family member’s body until it was collected from the hospital:
I just said to her … ‘can you promise me you'll stay with him’, she [the nurse] said ‘I won’t let him die alone, I’ll be with him. All the way through’ (Avril, wife of deceased).

I remember that nurse, she said when we were leaving and they were waiting for the coroner’s court to come and pick him up, and she said I’ll stay here, I’ll make you this promise, she said I’ll stay here with him until they come and get him (Henry, father of deceased).

Other families had different experiences, in another death, following donation surgery the participants noted that, although their family member’s body appeared cared for, the family felt left alone and deserted with their family member’s body. Their remaining trust was eroded because of their perception that the process was focused entirely on recovering organs from the deceased and not on caring for the deceased or their family that donated their organs. This view suggests that it is important for health care professionals to ensure they provide care and protection not only to the deceased but also to the bereaved family members before and after the death including the final viewing in hospital: Got left. So the room was really nice and it’s well set up. That was probably the best thing they did, but no, no-one ever came to look for us, care for us (Louise, mother of deceased).

Interestingly, one participant remarked on the importance of having just learnt that if an organ was donated and was unable to be used the family could request to have it returned to be interred with the deceased. This level of respect was seen by the participant to confirm a relationship of trust that should exist between the donor family and the donor agency to
demonstrate that the donor and the donation are valued: *The organ is returned and that shows so much respect and if that fact were highlighted …* (Ruth, mother of deceased).

The commitment of health care professionals to caring for the decision-makers’ family member was highly valued by the families, and several families noted that staff worked beyond their shifts to care for them and their family member, which helped to engender trust that the staff were doing everything possible to care for their family member:

*And they hadn’t gone home, they’d worked constantly, they didn’t want to leave him. And one of them had knocked off the night after his surgery, she’d already finished work but she was there on her own time. She said I’m not getting paid overtime, she said I’m here* (Henry, father of deceased).

The dedication of an emergency doctor in a regional location was valued by a participant that had provided consent for organ donation to this physician, believing he had the best interests of her family member in mind and had worked tirelessly in trying to save her son. The participant explained: *He’d actually stayed on duty for an extra hour and a half from when ‘Hamish’ [pseudonym] came in* (Ruth, mother of deceased).

Having familiar staff that knew the patient’s history and who had established a rapport with the family also appeared to contribute to the satisfaction of the decision-makers and their sense of trust that the people providing care to their family member were interested in and cared about the dying person and their family:
I honestly think having that familiar face and having that person that … knew the story …

You didn’t have to keep explaining it all the time (Jenny & Henry, parents of deceased).

I know it helped me when I was in the room, I was showing them photos of him. The fact that they were interested (Jenny, mother of deceased).

The participants’ continued sense of trust in the organ donation process appeared to rely on the transparent evidence that health professionals discussed the wishes of the deceased and clearly indicated they had checked all formal documentary sources for evidence of a decision about organ donation made by the dying or deceased person when discussing the decision with the family members. The participants viewed the efforts made by health professionals in checking documentation as a sign that the staff valued the deceased wishes. All believed their family member’s views should have been central to the donation decision, and honoured by the health professionals: From where I stand, if someone is registered as an organ donor, end of story. That’s it (Julian, brother of deceased);

All participants trusted there would be acknowledgement of the deceased donation, reciprocity or a thank you from the recipients or some other evidence of valuing of their relatives’ gift: She said, and just because of families like you we got a liver (Jenny, mother of deceased).

The ability to have health care professionals work in partnership with the decision-makers to ensure transparent, accurate information and empathic support and communication about their family member was central to trust protected. Compassionate care enabled some decision-makers
to trust that their family member’s best interests were protected enough to feel secure in making a decision to agree to their deceased organ donation without any regrets. However, despite having made the offer to donate, one participant described the disappointment of his family withdrawing their offer of organ donation because they believed the organisation was not equipped to meet their expectations: *It would be good if the system was better so Dad could have donated his organs* (Harry, son of deceased).

In conclusion, the sub-theme *Trust protected* encompassed all participants’ ideas regarding their needs for 1) compassion, protection and dignity for the deceased; 2) respect for the life meaning and wishes of the deceased; and 3) reciprocity and acknowledgement regarding the experience. The participants all described their responses to the threat to their family member’s life with ideas that encompassed the decision-maker’s own need to survive, to fight for and to defend their family unit; and importantly, to protect their dying family member and their families’ interests. This sub-theme identifies the significant role that trust played for participants’ who needed to be assured that there was no conflict of interest in the treatment provided to their dying family member, or in the relationships between themselves as decision-makers and the doctors and nurses. Having their *trust protected* led decision-makers to agree to organ donation, when they were assured with 1) transparent evidence of the provision of patient-centred care; 2) protection of the life meaning of their family member; 3) the provision of quality end of life care processes. The participants all presented ideas related to their expectations about transparent and informed consent decisions, and acknowledgement for the donation that was viewed as a gift. The participants with the most positive views of organ donation expressed satisfaction in knowing that everything possible was done to save their family member’s life and
to care for their other family members. This finding suggests that the organ donation process protected the dignity and life meaning of the donor as perceived by their family, when the process was performed in a compassionate and professional manner.

### 4.4.3 Theme Three: Harvesting humanity

The third major theme, *Harvesting humanity*, and its associated sub-themes, *Sack of body parts* and *Sacrificing peace at death* are diagrammatically represented in Figure 4.12.

*Figure 4.12. Theme 3. Harvesting humanity and its sub-themes*

The third major theme, *Harvesting humanity*, and its associated sub-themes, *Sack of body parts* and *Sacrificing peace at death* were the major theme and sub-themes that represented barriers and regrets to deceased organ donation. *Harvesting humanity* was an intrinsically negative overarching theme drawn from the participants’ narratives of hospital experiences that represented first, a lack of compassion; second, perceptions of conflict of interest; and third, regret regarding the experience. This overarching theme was bounded by the crisis event that
caused the critical injury, the recognition that death was inevitable, the diagnosis of death, the organ donation decision and its consequences. The name of this theme is drawn from the narratives of many participants that found the terminology used to communicate about organ donation brutal and distressing. The name of the theme was purposefully selected to represent the sense of horror and unnecessary hurt that many participants experienced related to their experience of deceased organ donation decision-making.

Many families felt that humanity was excised from their experience of the death of their family member and experience of making an organ donation decision by the doctors and nurses involved. Language played a significant role in participants’ conceptions of the relationship between their family member and health care professionals. Words such as ‘harvest’ were perceived as lacking in humanity and became a barrier to consent for some participants: I remember her talking about ‘harvesting’. I remember that word quite clearly. I felt very cold to the word (Sam, father of deceased). Linda describes how she felt after hearing the treating doctor refer to harvest when discussing the donation of her brothers’ organs:

*Harvested is not a word that needed to be used on any scale anywhere. Collected, removed, harvested! There’s a thesaurus full of words, and you use harvested…And you wanted … I’ll take the liver off you; I’ll take this off you! You don’t harvest anyone. It is a brutal word, a brutal word* (Linda, sister of deceased).

As previously mentioned, emergency doctors were the first to break the news to most participants about the extent of their family member’s injuries. They were also the first to explain that the injury was un-survivable to three decision-making participants. In two deaths,
emergency physicians first told the participants the extent of their family member’s injuries and the unlikelihood of their survival, and then raised the question of organ donation. In both these situations the participants provided agreement when asked. One of these decisions was made by the mother of the dying patient over the telephone, and the other decision was made in a private room in an emergency department. Both decision discussions occurred within hours of the critical injury leading to the deaths. In these two decisions, made while the patients were still being treated in the emergency department, the participants described how having agreed to organ donation before having understood the reality of the death, they fought to maintain hope that the diagnosis was mistaken. One participant described her anguish over having previously signed the organ donation consent documentation without having understood the implications her decision could have for her family member:

No, just that one feeling of anger with myself for having signed a document that was so important to our children, without researching it and knowing it first. You know, I was worried that whatever I said was going to make the difference between life and death for ‘Hamish’ [pseudonym] (Ruth, mother of deceased).

The participants from both these families believed they had provided agreement to allow deceased organ donation while suffering shock and before they had the time or sufficient information to understand the unfolding events. The participants spoke about how their agreements were based on the memory of their family member’s wishes and attitudes. Following the transfer of their family members from the EDs into the ICUs, the positive relationships between the decision-makers and the health professionals and these two families changed, with the introduction of new personnel, new environments and a failure to maintain support and
communication. These changes led to the participants’ experience of deep distrust towards the treating doctors and nurses. Despite their anxiety, neither family withdrew their consent; participants from both families explained that they felt powerless to act. The perception of medical conflict of interest undermined the trust of the participants in the motivations of the treating doctors, with decision-makers emphasising that they were fearful and needing to be assured that the treating doctors were focused on saving life, and not on their donation prospects:

*Just do everything you can to save his life* (Ruth, mother of deceased).

Ideas of conflict of interest and questions of distrust were represented in eight of the nine organ donation decisions and in the five consent decisions. The participants’ expressed feelings of dismay when exposed to insensitivity from health professionals. In one death the family, which had been considering agreeing to organ donation in the hope of honouring their family member’s wishes, felt compelled to decline because of the way in which organ donation was presented to them by the treating doctor:

*She said you’d say your goodbyes while the machine is on, and in two, maybe three days’ time, when everything is ready and everything is prepared, it is then that we take him in.*

*We’d open him up and we’d harvest the organs while the heart is still beating. And Mum’s just, No!* (Linda, sister of deceased).

Linda recounted that the reason why her mother declined organ donation on behalf of her family was because of the doctor had been unable to promise the deceased wouldn’t feel pain and because of her description of the organ donation process:
That would have haunted her to the end of her days … that her son would have, one, felt pain … and two, was going to be kept alive like a guinea pig before they harvested the organs (Linda, sister of deceased).

Participants from four of the five consent decisions spoke of how they sought to protect their family member’s interests, and had their trust in health professionals undermined when their dying family member’s interests appeared compromised. Decision-makers that were distrusting of the motivations of the health professionals or the care provided to their family member were less likely to agree to organ donation, and those that had already agreed described apprehension related to their decision and its outcomes.

Another participant but spoke of her families’ distress when their family member was transferred to a large metropolitan hospital ICU where treatment was withdrawn and DCD took place. The participants recalled their anger and distress when access to their family member in the ICU was blocked by organisational barriers. Poor communication, unreasonable requests of the family and perceptions of an ‘organ-centred’ approach to their family member’s care undermined their trust in the health professionals responsible for treating their son. According to Louise, the family distress and distrust was compounded when the family were left alone, away from the bedside for prolonged periods without information or support: So at that point they took him off to have the test done and put us back in the little box, and forgot about us, left us there … Two hours later … (Louise, mother of deceased).
The participants spoke about firstly being led to believe their family member was brain dead; a diagnosis that was changed when scans revealed blood flow confirming he was alive, but this was not communicated to the family who had agreed to organ donation believing their son was brain dead. The participants spoke about their distress that this information was not communicated at a time when organ donation processes were being arranged. Louise remembers the events that led to their family member’s death and DCD:

*And at no point were we ever told by a doctor the results of that angiogram, a nurse told us that there had been, there was still a small amount of blood to his brain. So because of that he would have to have cardiac death [DCD] (Louise, mother of deceased).*

The decision-makers described how they had remained largely uninformed about the condition of their family member. However, interpreted a subsequent comment by a doctor that their family member would ‘*never be the same*’, as meaning that there was a possibility of survival, suggesting that the original prognosis was incorrect:

*At that point I think Adrian and I had been told there was no hope. And then at one point they did almost slip up and the doctor made a comment that if he was to survive he wouldn’t be the same. So to make that comment sort of gives you something to grasp onto, and he must have seen our reactions. When I now know there was no hope (Louise, mother of deceased).*

The participants spoke about their perception that the health professionals were disinterested in their dying family member, his wishes or the meaning his life held to his family; factors that exacerbated the families’ distrust and perceptions of conflict of interest. According to
the participants, the cessation of treatment led to the death and organ donation within 24 hours of
the initial injury, and within 12 hours of his arrival in the ICU. Louise described feeling
powerless and unprepared for the withdrawal of treatment, her son’s death and DCD: They
decided when he would die; we had no say in that (Louise, mother of deceased). Louise
expressed regret about the way the events unfolded:

I almost feel like the emphasis was on the organ donation, rather than the care for him or
us. In that maybe if we had had more time before it was presented in terms of being brain
dead, it would have given us some time to absorb the fact that he was going to die
(Louise, mother of deceased).

Several other participants expressed their concerns regarding conflict of interest when
told by the treating doctor that their family member had died, and within minutes had the same
doctor request organ donation. Julian describes the experience:

Because all of us, you know, on one hand, they’re saying ‘Yeah, Stephen’s died.’ And
then you’re [the doctor] saying, ‘Well, Stephen’s died. Can we have him for spare parts?’
It should be introduced and left, and handled by a different medical team. Or, without the
doctors that have given you the news that there’s no recovery (Julian, brother of
deceased).

Another family that agreed to donation was satisfied with the care their family member
had received; however, they were shocked after agreeing to organ donation that their family
member would be taken away from them while her heart was still beating. This new information
created feelings of angst and bewilderment for the participants and led the family to decline
donation until their concerns could be addressed. In three other deaths in which organ donation proceeded, the participants trust was undermined by what they perceived as dehumanising organisational processes.

The participants from some families spoke about circumstances in which the health care professionals appeared uncertain about the requirements for organ donation, a confusion that they described as contributing to their unease and distrust in the situation. Decision-makers from five families that had consented to donation as well as those that had declined voiced their concern about believing they had experienced additional distress caused by perceptions of a lack of compassion or dignity for their family member and their family from doctors and nurses when communicating about organ donation, as well as in practices associated with caring for the family member when it became evident that there was no prospect for survival.

The experiences that caused participants additional distress throughout this period included their difficulty in processing new information and unexpected information for which they were unprepared. Ruth was particularly distressed because she could not understand if her decision to donate had influenced the treatment her son received, or her son’s survival prospects. In a different decision, Hannah expressed angst that she was ill equipped to anticipate what would happen next, both in terms of her family member’s changing treatment and condition, but also in understanding the organ donation process.

*I'll agree to it, to have the blood test, as long as you don't touch her face. I said that I supposed I wouldn't have any choice and she said, ‘No, I have to live with myself so I wouldn't do that if you don't want her face touched’* (Hannah, mother of deceased).
Participants expressed ideas that suggested they thought suffering could still affect the body even with the confirmation of brain death and believed it was judicious to quickly proceed to organ donation to limit their family member’s perceived suffering. This action was seen as preferable to having ‘life’ maintained on a ventilator for an undefined period. Moreover, some narratives suggested that some families would agree to organ donation as long as there were no delays in facilitating the donation despite brain death not being confirmed. This was because the participants perceived that there was no hope for their family member’s survival and they believed continuing treatment would contribute to suffering.

In conclusion, the third major theme, Harvesting humanity, is an intrinsically negative theme towards organ donation because it encompassed the participants’ experiences of first, a lack of compassion; second, perceptions of conflict of interest; and third, regret regarding the experience. This overarching theme was bounded by the crisis event that caused the critical injury, the recognition that death was inevitable, the diagnosis of death, the organ donation decision and its consequences. The name of this theme is drawn from the narratives of many participants that found the terminology used to communicate about organ donation brutal and distressing. The name of the theme was purposefully selected to represent the sense of horror and unnecessary hurt that many participants experienced related to their experience of making a deceased organ donation decision. The findings suggest that doctors and nurses deeply influence the experience of decision-makers and require skills of compassion, sensitivity and empathy to care for families of dying and deceased patients. The findings also suggest that there is much that
can be done to address clinical barriers to organ donation situated in insensitive practices and fragile relationships between families and health professionals.

4.4.3.1 Sub-theme 3.1: Sack of parts

The sub-theme Sack of parts sits within the intrinsically negative overarching theme Harvesting humanity, and encompassed most participants’ experience of discussing organ donation with health professionals during the decision-making experience. It encompasses first, disrespect of the deceased; second, taking without thanking; third, harmful bureaucracy. Some families that had already agreed to organ donation found the process of organ donation decision-making involved distressing new events. For the most part, the narratives that relate to this theme come from the decision-makers that agreed to the donation of their family member’s organs, and their descriptions of their subsequent experiences. The participants’ interpretations and understandings of organ donation processes were obtained from the communications they received about organ donation from doctors and nurses responsible for caring for their family member. The name of the theme was drawn from the participant narratives.

The interaction that appeared to have the most damaging effect on the families in this study involved their requirement to complete detailed and explicit consent documentation to allow the surgery to proceed, which undermined their trust in professionals to protect their family member from harm: The discussion was confronting. A recitation from a spare parts catalogue. Fuck you don’t need that (Julian, brother of deceased).
In some situations the dignity of the dying or deceased was threatened by doctors that held discussions with family members about the possibility of organ donation. In other circumstances, the difficulties arose after the organ donation decision had already been made, and when donation staff became involved. The administrative processes to enable the efficient transplantation of the donated organs from the deceased donor contributed significantly to participants’ distrust in the quality of respect and care that was being afforded to their family member in two cases of consent to donation. Some participants felt that if their family consented to organ donation their family member would be relegated to becoming a *sack of parts*, an idea drawn from participants’ interpretations of their conversations with the health care professionals involved in the treatment of their family member. Some participants described how ideas of dissection were evoked in their minds when providing formal agreements for the donation: *You could have very easily construed some parts of the process we went through as almost being body snatchers* (Julian, brother of deceased).

Sam described having the organ donation process described to them by a doctor involved in determining the brain death of his son. He was shocked by the description which he viewed as harmful and de-humanising: *the difference between a human and then he’s a commodity. Like magpies, crows or something* (Sam, father of deceased).

Similarly to Sam and other participants in this study, Linda wished to highlight the harmful effect that using terminology such as ‘harvest’ had on her experience and understandings. These participants wanted to reveal the harm caused by the use of such terminology; and the effect on the recipients of declines associated with the use of the term, and
the lack of staff appreciation for the grief, shock and distress that knowing a family member has died evokes in family members. This also has implications for their communication needs: So it was put to us that bluntly, Stephen’s dead and Stephen might be able to do something [donate] for someone else (Julian).

Linda held a similar strong view after being present for a conversation with a doctor in which organ donation was described using what she described as a very agricultural manner and without evidence of compassion for her family member. Linda presented ideas that also drew from the media representation of fears about organ donation practices and alleged myths of donation. This conversation is described by the participant as having been also heard by a very large group of family, friends and pastoral care support that may have also been dismayed by its use and context:

*Harvested is not a word that needed to be used on any scale anywhere. Collected, removed, harvested! There’s a thesaurus full of words, and you use harvested…And you wanted … I’ll take the liver off you; I’ll take this off you! You don’t harvest anyone. It is a brutal word, a brutal word* (Linda, sister of deceased).

The narratives of participants from four deaths included their ideas that their family members were seen as being relegated to becoming a *sack of body parts* upon their death or as they were dying. Many of the participants described how the health care professionals engaged in the care of their family members appeared to relegate their body to becoming a vessel for organs. Many participants perceived that their family member was stripped of their dignity and meaning by the organisational processes required for organ donation. Many participants felt that
the staff engaged in arranging the organ donation and completing the requirements treated the participants’ family member not as a person, but a sack of body parts. These perceptions contributed to the sense that organ donation was not only a donation of organs, but had become a sacrifice of dignity, humanity and peace at death: *I’m sure Dad would have wanted us to be happy rather than his body remaining a vessel for these organs until someone would come and remove them* (Harry, son of deceased).

Wherever suspicions of conflict of interest already existed for participants were catalysed by health professionals insensitivity and failure to consider the needs of the families to see that their dying and deceased family members were treated with dignity. This apparent lack of compassion, empathy and professionalism contributed to some participants’ refusal to continue to discuss the organ donation:

*And I think the thing that I remember most about the discussions, and at one point we just, we said ‘No, you’ve got to stop this. We can’t do it.’ Because they were actually almost describing the surgical procedures for taking the organs* (Sarah, sister of deceased).

*That’s what struck me when we are at the hospital, and they were mentioning parts of Stephen’s body, like is it OK to take this part, and is it OK to take this part, and it was just, Stephen was a human, Stephen was a friend. Stephen wasn’t just a bag of …* (Helen, sister of deceased).

*At the end of the shopping list* (Louise, mother of deceased).
A perception of failure to adequately acknowledge the donation decision further contributed to a perception that their family member’s donation was not appreciated but was instead seen as a ‘harvesting’ of organs from the deceased body without acknowledgement of the dignity and meaning of the person to their family:

But it was more so the fact that we’d felt they’d be just taking, taking, taking, and we had nothing left. But no-one had ever asked, what can we do for you? It was just we’re taking this now we’re doing this now, everything was running on a schedule, no-one actually turned to us and said, do you mind if we do this? It was all regiment (Lucy, sister of deceased).

The participants from three families that agreed to donation described events that contributed to their sense of feeling disempowered by the processes. Louise and her family had agreed to donation but described that they were never provided with the information or support that they required to enable them to feel content that they had made the correct decision in agreeing to their family member’s organ donation:

That’s what I said, it’s like stepping into the rat wheel, they put you into it and you just go, there’s no time for you to stop and think or really make conscious thought-out decisions about what’s happening, where you’re going, any of that. For us this was all so very short and quite rushed, in that it was always about getting the organs, it wasn’t about caring for Kieran (Louise, mother of deceased).

In conclusion, The sub-theme Sack of parts sits within the intrinsically negative overarching theme Harvesting humanity, and encompassed most participants’ experience of
discussion organ donation with health professionals during the decision-making experience. It encompasses 1) disrespecting the deceased; 2) taking without thanking; 3) harmful bureaucracy. Some families that had already agreed to organ donation found the process of organ donation decision-making involved distressing new events. For the most part, the narratives that relate to this theme came from the decision-makers that agreed to the donation of their family member’s organs, and their descriptions of their subsequent experiences. The participants’ interpretations and understandings of organ donation processes were obtained from the communications they received about organ donation from doctors and nurses responsible for caring for their family member. The name of the theme was drawn from the participant narratives.

4.4.3.2 Sub-theme 3.2: Sacrifice of peace at death

The sub-theme, Sacrificing peace at death sits within the intrinsically negative overarching theme Harvesting humanity and represents the participants experience and fears of first, suffering; second, the loss of the sanctity of death; third, not honouring the deceased. Participants sought help to ensure that their family member’s dignity and life’s meaning was protected. Ideas of a peaceful death included opportunities to talk about their family member and ideas relating to honouring their wishes. Interference in the family’s ability to care for the body of their family member and protect the meaning of the family member’s life was revealed in this sub-theme. The name of the theme was drawn from participants’ ideas of sacrificing peace at death with health professionals seen to relegate the body to a utilitarian status without dignity or meaning. This belief influenced some participants to fear that the life meaning of their family member was irrelevant to those responsible for providing care to their body. This finding is contrary to the human rights ideal of the right to a peaceful death.
Most participants expressed regrets that the hospital processes and practices surrounding end of life care, death and organ donation presumed families would know ‘what to do’ and understand what was involved when a family member died in the ICU. They argued that staff focused on the requirements of the organisation and excluded the needs and wishes of the dying patient and their family. This contributed to the participants’ perception that organ donation required the sacrifice of a peaceful death. These ideas left the decision-makers in this study feeling anger, resentment and regret. These experiences may have complicated their bereavement and negatively influenced future donation decisions of their family, friends and community.

The idea of organ donation was generally supported by all the participants that contributed to this study, and yet the analysis identified a preponderance of negative themes. This was despite the narratives of participants from five families that agreed to organ donation compared to four families that declined to donate their family member’s organs. Many participants were disappointed to find their hopes for altruistic organ donation and ideas of a peaceful death appeared mutually exclusive in their experience of end of life care and organ donation practices involving their family member. The ideal of hope for a peaceful death was strongly represented by the participants as they described their efforts to negotiate the activities of end of life care and organ donation processes within the health care environment.

Participants’ ideas of honouring their family member’s life meaning and body with the goal of a peaceful death and organ donation, appeared subsumed by the clinical practices and governance requirements of death and organ donation. The information about the organ donation process was new to most participants and they described their frustration in not knowing how to
manage the situation, or how to create the environment they believed would have afforded their family member a more peaceful death: *So I suppose from that point of view we knew it was ‘Kieran’s’ [pseudonym] wishes, but I don’t think anything prepares you because none of them are prepared to say what happens after you say, OK* (Louise, mother of deceased).

Decision-makers said they were shocked to discover that once they had indicated agreement to organ donation they were then required to complete what they perceived as onerous formalities. This requirement meant that family members that wanted to be at a family member’s bedside were delayed because of the necessity to complete the consent interview and medical and social history. This delay contributed to the sense of sacrifice some families felt, especially if they had just arrived at the hospital had not been able to see their family member or receive an update on their family member’s condition by a health professional involved in the care: *Because we’d already said yes, we didn’t realise we’d have to go and be separated and go through this, the whole thing sort of again* (Louise, mother of deceased).

The families appeared to depend on nurses’ empathy, compassion and information, and struggled in making sense of what they saw when visiting their family member at the bedside if compassionate support and information was not provided by nurses. A participant describes the difficulty she experienced in understanding the situation because she was not guided or supported by the nurse: *She was reasonably young, and I don’t think she could handle it. We would have to ask. I said, well why is he bleeding so much from his ears still, and, nothing was first forthcoming and certainly no support for us whatsoever* (Louise, mother of deceased).
Another participant described the difficulty they encountered when a donation nurse conducted an interview with them: *She tried about six times to come and do it with us didn’t she? She would just burst into tears every time she’d do it. And so I get the whole it would be hard* [conducting the interview] (Henry, father of deceased). Although the family appreciated the sensitivity of the staff that expressed emotion and compassion for their circumstances, it was highlighted by Henry that it was important for the family to have steadfast support from the staff involved in the situation: *I guess in that situation you’re looking for a rock* (Henry, father of deceased).

The process of trying to understand what was expected of them in allowing their loved one to donate organs required the families to use cognitive and emotional energy, and the participants’ descriptions of their experiences reflected a sense of courage and sacrifice in their efforts to maintain hopes to donate. These factors also challenged the participants’ decision-making integrity because they forced family members into a position where they were required to consciously make a donation decision based on relational trust and not rational understanding: *But then when we realised it wasn’t going to happen the way we’d imagined we really had to rethink it. And we had to reframe the whole idea of at what point she would die* (Brittany, mother of deceased).

Perceptions by decision-makers that health professionals could create barriers to a peaceful death by allowing a family member to be ‘maintained’ in a suffering state until organ donation surgical processes could be instituted contributed to ideas of distrust. In one death a family that had agreed to organ donation threatened to withdraw their agreement to donation
because of the emotional trauma they perceived when undertaking the consent interview with the donation staff. In a second death the participants reported that the interview caused them great distress but they were too shocked at the time to realise they had the power to withdraw their agreement or to negotiate with the staff. In a third death, the family withdrew their agreement to donation when first learning about the organ donation process from the donation staff; they subsequently reconsidered this decision and ultimately agreed to the donation.

The participants expressed concerns about how their family member’s known wishes about organ donation were managed. Conceptions about honouring the dying person were undermined when family members discovered the family members’ organ donation wishes appeared irrelevant. The participants were aware of government efforts to increase rates of organ donation and most of them had taken active steps to discuss organ donation with their family; some were aware their deceased family member had previously officially recorded their consent to donate. Many participants had registered their own organ donation wishes trusting they would be valued: We’ve always been registered (Jean, mother-in-law of deceased).

The idea of false hope, deception and distrust became evident in three deaths when the participants described their frustrations in finding that their family member’s wishes, which had previously been documented according to regulations, appeared to have been dismissed or ignored. Ten participants questioned why the public were asked to formally document their organ donation decisions, if the information wasn’t actually used at the time of deceased decision-making, suggesting that the views of the deceased and their hope to donate were considered irrelevant:
One of the most hurtful things was that Stephen’s opinions no longer mattered because he was dead. Stephen still matters. Stephen still matters to us (Helen, sister of deceased).

What I think is interesting about the whole organ donation thing is that, sure, it’s on his driver’s licence, but it didn’t seem as though they checked any of that. It was more like it was a family decision. If I was to pass away and I’m an organ donor, do I have any say? (Ian, brother of deceased).

He made that decision. He thought about it before he did it, he knew what he wanted (Linda, sister of deceased).

We weren’t asked, no, nothing to do with ‘Kieran’s’ [pseudonym] wishes (Louise, mother of deceased).

Participants from this family described how the events unfolded; after having agreed to donation they were informed that the donation process required their brain dead family member to be taken to the operating theatre on a ventilator alone for the donation surgery. The participants recall they were shocked and unprepared for this information and described how they had imagined a more peaceful experience based on ideas that they believed were probably drawn from media. They had previously believed their family member would have treatment removed, and die in their arms before being taken to the operating theatre:

I never knew that. Everyone has got this lovely Hollywood image in their head about sitting with their child, or their mother, or father, or whatever, until they stop breathing, and then they come and take them away. But it can’t happen like that, I mean it’s logical. But we were shocked by just being confronted with that, right at the very worst time (Brittany, mother of deceased).
The new information that their family member would be wheeled away while their heart was still beating despite being declared brain dead contributed to further trauma and the sacrifice of peace at death because it was new and unexpected information:

*It’s just a shame that we didn’t know this from the start. I think the problem is media and I suppose Hollywood, that kind of image of people, sitting there holding someone’s hand as the machines are switched off and they quietly slip away and I think that’s kind of the image we all have in our heads. And of course it doesn’t happen like that and it can’t happen like that. So I just think if we’d been better informed from the start or before it wouldn’t have been as traumatic* (Joelle, aunt of deceased).

Brittany discussed how she and her family having been given this information were able to make sense of it after having been given some time to understand the physiological practicalities. One participant describes how the decision-makers started to negotiate with the staff and eventually took ownership of the situation. The decision-makers were unable to continue with the organ donation process until they had been able to reconcile the new information:

*Well they explained why that couldn’t happen, because it has to be a beating heart donation basically they said, ‘We can do that, we can disconnect the oxygen and everything else, and you can stay there until she stops breathing, but then we can’t use any organs.’ And you know, when you think about it when you’re not upset, it makes perfect sense. But none of it makes sense when you’re in that state of mind* (Brittany, mother of deceased).
The health professionals gave them time to rethink the situation and removed themselves from the discussions. The participants recalled how the family members devised a way of creating the ritual required to enable them to more gently separate from their family member’s brain-dead body as it was taken to the operating theatre, in a way that met their needs and hopes to afford their family member a peaceful death, and dignified parting and organ donation outcome:

*We’ll shut the doors and say goodbye. And I said, ‘We’ll tell you when you can come and take her,’ and so we did, and we were there for about 10 or 15 minutes I think, and then we called them and said, ‘You can come and take her away now,’ and then they took her, because we couldn’t have walked out and left her* (Brittany, mother of deceased).

Although in this death, the participants were provided with adequate time and support to enable them to come to terms with the new expectations about how the parting would be facilitated, the staff were also very open and supportive of the family seeking to ensure they didn’t feel pushed or coerced in any way, which was appreciated by the participants:

*I do remember the hospital staff coming in and just saying ‘You don’t have to do this, there’s no pressure’ like being very reassuring and just making sure that the family weren’t being put under any sort of undue pressure there and that was also reassuring* (Joelle, aunt of deceased).

The confusion related to decision-makers’ lack of knowledge of processes of organ donation was compounded by inadequate information or support contributed to significant distress for many participants. The participants used a range of ideas based on media constructs
or assumptions of what they imagined would logically occur in an organ donation process to try to image what ‘will happen next’ in the care of their family member and to enable the organ donation process. One family provided an example of how this cognitive dissonance contributed to their grief at the time of their family member’s death. This occurred in circumstances that evolved when the family present at the bedside saw bodily changes which they realised meant that their family member had died, and heard the monitor alarms. Within minutes of this event, the mother offered the body to the treating doctor. They were bewildered when he declined their offer: *I nodded OK, you can take him now; and that's when he said, 'No, he can't be an organ donor now, it's too late’. And he made us feel like it was our fault* (Ruth, mother of deceased).

Ideas of prolonged suffering in the midst of what the family members perceived as a horrifying environment also contributed to decisions to decline organ donation. This family felt accountable for their decision, which they believed would have resulted in the dehumanising act of allowing prolonged suffering for their family member if they had agreed to donation. Avril described that the doctor had explained that her family member’s condition would continue to deteriorate, and the physical signs of suffering that she had witnessed at the bedside would worsen over time: *It's going to get worse, it will get worse, the way you see him now, it won’t stay the same, it will get progressively worse. We have to do certain things to keep him stable* (Avril, wife of deceased).

Participants described how difficult they found the idea of separating from their family member’s body and related distress around the idea of ‘letting go’ of the family member’s body. The relationships with health care professionals deeply affected the experience and interpretation
of the events for the family members. The participants were anxious to know that their family member was cared for and described asking questions at the bedside, of treating doctors and nurses while keeping vigil. Several participants described callous and insensitive communication between themselves and health care professionals, which undermined their trust in the motivations of the staff. Hannah related an event that occurred at her family member’s bedside when she asked a doctor about her daughter’s progress:

He didn't even say hello when he came in the room, just went to testing. It almost becomes like it's not a person anymore, it's not my daughter, it's not someone's family member but it's just a patient they're attending to. When I said to him about her high blood pressure he just said—and I don't even think he turned around—something like ‘She’ll be dead in a day or two’ and I just burst into tears. He explained why and apologised then. He could have handled that nicer (Hannah, mother of deceased).

The need for participants to assure themselves their family member was not suffering before agreeing to organ donation was clearly represented in all the narratives in this study. The answer appeared to require visual as well as verbal proof for the decision-makers involved in this death, a need which was not satisfied by the doctors’ response that he was not suffering, when the family believed they were witness to his suffering and were fearful it would be prolonged if they agreed to organ donation. The need to protect a family member from perceived suffering overrode any desire to agree to their previously known wish to donate:

They could not guarantee that she would feel no pain … So we turned around and said ‘no’, if you can’t guarantee my daughter will feel no pain, then no (Linda, sister of deceased).
The moment we were told what was involved with keeping him alive long enough to
donate those organs. The doctors and the nurses left us alone to make the decision, and
we all looked at each other and then we talked, and we cried, and we said we can’t do
this to him any longer. You couldn’t watch a TV show and see an animal suffering (Avril,
wife of deceased).

As mentioned previously, some organs were ascribed with special characteristics by
decision-makers, in particular the value of the heart. Also, as previously described, the
interchangeable use of the terms ‘organ’ and ‘tissue’ by the community contributed to confusion
for participants in this study and appeared to increase the level of suffering experienced by one
family that had agreed to donation but believed that the eyes would be taken without
consultation: He’s going to be an organ donor. They’re going to take his eyes (Ruth, mother of
deceased).

A participant from a different family, that had initially declined donation, changed her
mind and agreed to donation, but only after being assured by the donation nurse, that if the
donation went ahead, her daughters’ face would not be touched. In four deaths in this study,
participants described how members of their families were accepting of the idea of donating
organs, but objected to donation that was perceived to disfigure the deceased body: Nothing on
the outside (Linda, sister of deceased). The participants were uncertain about the processes
involved in eye donation which may have created a barrier to their donation: Lucy [sister of
deceased] objected to his eyes, because she said, they’re the windows to your soul. But in saying
that at no time did they ever explain how that would happen if we’d consented (Louise, mother of
the deceased). The idea that the eyes carried special qualities that excluded them from donation was held by Lucy with regards to her brothers’ donation, but also by Harry, concerned for the well-being of his deceased father: *It was only Harry [son of deceased] who got all a bit airy fairy saying you can’t have his eyes. They are the window to the soul* (Avril, wife of deceased).

The theme of ‘prolonged suffering’ and ‘family’ suffering also strongly influenced Avril’s and her family’s decision. The family just wanted to get away from the traumatic scene, evidenced when the family left the hospital before the extubation and cessation of ventilation:

> *It’s going to get worse, it will get worse, the way you see him now, it won’t, it won’t stay the same, it will get progressively worse. We have to do certain things to keep him stable. We have to keep the machine going for him, and we will have to inject this [fluid] to keep the organs* (Avril, wife of deceased).

> *Mum sort of told us what to expect. Saying it’s not going to look good. It’s not like it’s going to be this beautiful man. He had bruising on his head and he had black eyes and all that sort of stuff from the damage* (Ian, son of deceased).

The idea of sacrificing peace at death encompassed a sense that the sanctity of death had been lost. Families who fell within this theme felt alone, without help and not knowing when and how they would say goodbye and part from their loved ones’ body. Families needed help the need to create the ceremony and ritual to allow a loving goodbye and release of the family member’s body, as described earlier by Brittany who with her family declined donation until they could structure a way to say goodbye, thus agreeing to donation, but on their terms: *We couldn’t have walked out and left her* (Brittany, mother of deceased).
Other participants also spoke of not wanting to sacrifice the peace of a loving and final separation. Hope for a peaceful death and the ability to provide the rituals of care that are associated with a peaceful death were important to the families with efforts to find enduring hope in loving farewells enacted in both non-donor and donor situations. Hannah described how after her daughter had been confirmed brain dead and while still ventilated before the treatment was withdrawn, she and her family cared for her family member’s body: We dressed ‘Amelia’ [pseudonym] in a beautiful gown and a friend did her make-up and she just looked like Sleeping Beauty (Hannah, mother of deceased).

Participants were fearful their family member was suffering and if alerted to any perception of suffering, appeared to immediately hesitate, testing their knowledge and seeking more information to ensure themselves their family member was being properly cared for. For a family that declined organ donation, the idea of a peaceful death came after their family member had life-sustaining treatment removed: And I just felt this sense of peace … that he was resting at that point (Avril, wife of deceased). In another death, a mother reflected that the final donation decision, that she and her husband agreed was legally and morally their daughter’s spouse’s responsibility; was ultimately made by the mother of the deceased:

No, because ‘Anthony’ [pseudonym] said no. I think he did it for me … I can’t say I’ve got any regrets because maybe if it's a different situation. It's a big thing. To this day I haven't felt guilty that I didn't do it but in different circumstances (Hannah, mother of deceased).
Many of the participants also described a sense of guilt, feeling concerned when they visited and sat with their family members or spoke privately with the doctors or nurses that they may have caused additional distress to families of other patients co-located in the environment. The participants appeared to accept that there was little opportunity for privacy in the design of the ICU’s they visited, but they expressed guilt when describing how other families were asked to leave waiting rooms to enable the families to have private discussions with the doctors. Notions of noises, smells, sounds, signage and fatigue appeared to contribute to the loss of peaceful death. The idea of witnessed suffering and surviving in the midst of horror was presented by some participants as they suggested that they struggled with the critical care environment; the noise of the machines, alarms and the physical evidence of their family member’s bodily failure assaulted their senses. One family was shocked to see a body wheeled past them while they were speaking to the doctor about the donation of their family member’s organs:

And here we are, discussing a dead man. And they were wheeling another one along the corridor. I suggest as much as timing is important; so too is place. You’re never going to find a good space to discuss these things. But, the message I’m delivering loud and clear is that the whole thing needs to be less confrontational (Julian, brother of deceased).

Several participants spoke passionately about their frustration of feeling unheard, unseen and unrecognised by the health care professionals caring for their family member. The individuals that experienced this suffering believed they were vulnerable and especially ignored in the circumstances because of complex relationships and because of their age. This was
particularly commented upon by Sam, a father; and Lucy, a sister, who felt passively excluded from the discussions by the health professionals and silenced by organisational practices:

But what really pissed me off in that conversation was that she never once looked at me (Sam, father of deceased).

But at the time being 16, I guess I can comprehend that you think we’re young. But we’re there and you can treat us like human beings. So don’t disregard us just ’cause of our age … that infuriated me (Lucy, sister of deceased).

The idea of sacrificing peace at death was very important for many of the participants that experienced the decision-making process of deceased organ donation. The idea of witnessing their family member suffering, perceptions of suffering, and fears of suffering contributed to family anxiety about agreeing to organ donation. The participants appeared to view themselves, as decision-makers, as being responsible for, and complicit in, the suffering of their family members if they agreed to the extended time frames they were told that it would take for donation surgery to be arranged. They saw themselves as their family member’s protectors and advocates and were distressed when they came to realise that organ donation also entailed a sacrifice of dignity and humanity that was caused by the way in which the organisational requirements for the donation were approached by health care professionals. They believed that they sacrificed the opportunity to grieve at the bedside in peace and solitude, with the still warm body of their family member:

I don’t think they have an understanding of exactly what donor families go through and what you give up. Put yourself into this really turbulent discussion room, and all the comings and goings and all of that. Where, if you didn’t do that, it would just be much
more peaceful, much quieter. I think they forget that you give up that time straight after death, rather than having him die and having him whizzed off, you only see him a couple of hours later when he’s colder and everything (Louise, mother of deceased).

I think it’s a very big ask on relatives to have to go through all that after the death. You know, first you’re accepting the death of your child or your parent or whatever. And then there’s another set of traumas that I don’t think are necessary. Well, it became traumatic. I don’t think it needed to. That’s the point I’d like to make (Julian, brother of deceased).

It’s your family member and it’s such a big sacrifice to you, to give even though you say ‘Well, they’ve died and it’s a waste if they just bury them’. But it’s still a huge, huge thing to ask a parent, to give away their daughter or son’s parts. I wouldn’t think twice of donating a kidney to my own child if they needed one but I just don’t know. I think we do need more education (Ruth, mother of deceased).

A perceived failure to acknowledge the gift of organs contributed to a sense of sacrifice and had implications for ongoing bereavement for one donor family. Personal support was not available to care for the bereaved that had declined organ donation, nor for some that had agreed at the time or following the events. One family believed the lack of acknowledgement or support from the organisation that facilitated the organ donation process added weight to her family’s sense of sacrifice. The participants questioned how it was possible to give a lifesaving gift of organ donation and not receive a letter of thanks from the recipient or appropriate acknowledgement from the organisation for the sacrifice of peace that the family endured by
agreeing to organ donation: *How can you not say thank you?* (Louise). They presented the view that many in the community may perceive that the decision to donate is too hard, and has few recognisable benefits for the family:

*I think people probably do it to protect themselves, and certainly in our case we have a whole lot of grief, because we said yes, and I don’t think that’s fair. It’s hard enough to lose your child without having all this other crap that you have to deal with. And really just then continue on unsupported* (Louise, mother of deceased).

The families of organ donors in Australia are told that it is not possible to meet the recipients of the donor organs, and they are actively discouraged from seeking them out, and most donor families do not receive correspondence from the recipients of their family member’s organs. This may not be known to the families that declined organ donation who also described ideas of meeting or knowing more about the recipients. Participants’ ideas and hopes about meeting recipients, communication between donor families and recipients and ongoing acknowledgement for the decision to donate were found to be poorly informed. Many of the participants’ ideas of meetings recipients are not possible in practice because of policies designed to create barriers between the different parties. However, this was not known to the participants at the time they were making their decisions and had implications for the expectations of some donor families that were hoping for acknowledgement or communication with recipients. Louise reflected that following their experience of donation, her husband, who had previously agreed to donate, would no longer do so because of his experience: *If we ever ask my husband about it, he says, they got what they wanted, we didn’t matter* (Louise, mother of deceased).
Many participants expressed disappointment when it became evident the organ donation process was not what they had expected, therefore undermining their trust in two ways. First, trust was undermined by a perceived failure of health professionals to identify and discuss the deceased person’s documented wishes; and second, because of the participants’ belief that they had insufficient information to provide informed consent when previously completing their own organ donation consent documentation and also when deciding about their deceased family member’s organ donation. The idea of not having expectations met, of losing trust in the processes of organ donation and of being ‘tricked’ into agreeing to a process that was not consistent with the participants’ ideas of informed consent were strongly represented by participants that had agreed to organ donation both by signing personal consent documentation on donation registers and also following the death of their family member: *It’s almost like they’re tricking people into agreeing by not giving them all the facts, because if they really know they might say no. You know, that’s what it appears like to me at the moment* (Christophe, father of deceased).

An important finding within this theme is that some families that declined organ donation also suffered distress and a loss of peace at death and this related to end of life care practices in ICU. Their experiences of suffering were influenced by the sights, smells and sounds that they described as horrifying when ‘life support’ was removed. This finding suggests that the loss of peace may relate more to the skills involved in caring for dying patients in the ICU than organ donation practices per se. Linda described what she witnessed when her brother’s ventilation was withdrawn: *And then we turned off the machines and it was absolutely horrific! Oh God I couldn’t even look at him; the smells*. Another participant, Hannah recalled her distress in seeing
her daughters ventilator removed: I’ve never seen anyone come off a ventilator and my son and Anthony [pseudonym]. When they turned it off the body goes into spasms and I just held her on each side. Anthony said ‘I can’t stay in here,’ and Scott [pseudonym] ran out. Scott didn’t want to see ‘Amelia’ [pseudonym] like that.

Another participant experienced additional suffering caused by guilt in not being able to honour their loved ones’ wish to donate. Nicole described her despair when her brothers’ wishes could not be honoured:

_I remember holding on quite strongly to the fact he wanted to be an organ donor, like it’s what he would have wanted. Then when they said ‘no, he can’t be’, it was another huge crack in the emotions. Oh we’ve just lost him, now we’ve just lost seven other peoples’ lives_ (Nicole, sister of deceased).

All families believed that the public should be provided with more information about the organ donation process. They also suggested that health professionals should be better prepared to care for and answer questions from families regarding dying patients who may become organ donors. They recommend that insensitive behaviours and delays in the organ donation process should be addressed, while making room for the rituals and respect associated with a peaceful death. Julian emphasised that the donation decision was inherently conflicted, and it was therefore possible to predict and mitigate its associated trauma:

_It’s the collision of two worlds. And, that’s predictable. I would suggest that the impact of that collision is minimised as much as possible out of consideration to the donor family_ (Julian, brother of deceased).
In conclusion, the sub-theme, *Sacrificing peace at death* represents the participants’ 1) fear of the family members suffering; 2) the loss of the sanctity of death; 3) not honouring the deceased. Most participants expressed regrets that the hospital processes and practices surrounding end of life care, death and organ donation presumed families would know ‘what to do’ and understand what was involved when a family member died in the ICU. They argued that staff focused on the requirements of the organisation and excluded the needs and wishes of the dying patient and their family. These experiences contributed to the participants’ perceptions that organ donation required the sacrifice of a peaceful death. These ideas left the decision-makers in this study feeling anger, resentment and regret for what they believed was avoidable suffering. These experiences may have complicated their bereavement and negatively influenced future donation decisions of their family, friends and community. This finding is contrary to the human rights aspiration of the *right to a peaceful death*.

**4.5 Conclusion**

In summary, three themes comprising *In the fog drowning, It’s all up to Mum* and *Harvesting humanity*, were presented. These themes encompassed decision-makers’ fears and the need to protect their family member and family from suffering; and found women, and in particular mothers played a significant role in decision-making. The findings showed that the decision-making process was positively influenced by transparent information and compassionate, experienced health professionals that collaboratively allowed family to partner in the care of their family member. Some families were able to experience a more peaceful and dignified separation from their family member by engaging in rituals of peaceful death. These practices led to a positive view of the death and the donation decision. Decision-makers that
were able to realise their hopes for a peaceful death and deep hope to find meaning from the
death agreed to deceased organ donation without regret.

Some families formed the view that organ donation was a sacrifice that was too great for
the deceased and their family to endure, even if the deceased had previously indicated an intent
to donate. It is clear that many participants found it difficult to find peace in the organ donation
decision for a range of rational, relational and emotional reasons. The participants in this study
were strongly of the view that much of their personal distress and anxiety about the organ
donation decision was avoidable and related to fear associated with a lack of information about
the organ donation process, insensitive practices and the idea of conflict of interest. In Chapter 5,
I will present the major conclusions drawn from these findings. Implications and
recommendations for policy and practice will be addressed, and recommendations for future
research will be provided.
Chapter 5: Conclusion

5 Introduction

In the preceding chapter I presented the major themes and sub-themes from interviews with participants who had been involved in the family decision-making process of deceased organ donation. Chapter 5 presents the major conclusions that arise from these findings, and will be discussed in association with the theoretical framework and literature previously discussed in Chapter 2. First, the chapter will present a reflective discussion of the modified Precaution Adoption Process Model followed by the major conclusions. Second, the implications and recommendations for policy and practice will be identified and discussed. Finally, recommendations for further research will be identified and described.

As previously discussed, the purpose of this study was to identify the major factors that influence a family to agree or decline deceased organ donation during the process of decision-making. The aims of the study were threefold; to identify the key stages and the major influencers’ in the decision-making process; to determine if hope, deep hope and trust play a role in the decision, and to explore families’ perceptions of their decision-making experience.

5.1 Reflection of the Modified Precaution Adoption Process Model

The theoretical framework that guided the entire study is described in Chapter Two. It was based on Weinstein’s (1988) Precaution Adoption Process Model (PAPM) of decision-making. Weinstein’s (1988) decision-making model was structured around the concept that preventative health care decision-making involves balancing changing ideas of cost and benefit
along with cues to action which occur over time, and may not be based on rational factors (Weinstein, 1988). The underpinning constructs that guided the inductive development of this eclectic theoretical framework were rooted in the participants’ narratives, the literature, and the researcher’s clinical experience. The PAPM Model was initially modified to include the constructs of hope and deep hope underpinned by trust as the researcher believed that an eclectic framework could provide a more nuanced approach to help explain the complexity of family experiences of death and organ donation decision-making. Thus, the model was specifically developed and utilised throughout the entire study to explore the family decision-making process of deceased organ donation.

The initial idea for the use of the construct of hope and deep hope came from my observation as a clinician, of grieving families who had made organ donation decisions at the time of their loved ones’ death. I observed that some grieving families seemed to find strength in their decision to donate their dying or deceased family member’s organs during the time they were awaiting the arrival of donation surgical teams. Throughout these experiences I observed the differing ways in which the donor and non-donor families approached their donation decisions, and noted the differences and similarities in their behaviours. Of particular note was the way in which many donor families closely engaged with the care of the deceased and appeared to reframe their ideas of survival and hope. Some showed considerable interest in the continued functioning of their deceased family members’ organs. For example, I remember a relative helping to check the amount of urine produced by their loved one, and wanting assurances that the measure was sufficient to enable the donation and help recipients. Despite
their grief, these remarkable people appeared transformed with hope when anticipating the meaning the donation could have for recipients and their families.

There are three major conclusions from this exploratory case study, set in Australia, of the family decision-making process of deceased organ donation. These conclusions address the purpose and aims of the study. They comprise:

1. deceased organ donation decisions involve 4 key decision points
2. hope, deep hope and trust influence donation decisions
3. most families perceived organ donation required the sacrifice of peace at death.

In order to help the reader better contextualise the findings from this study, I will now reflect on the usefulness of the theoretical framework utilised in this study, and propose a new Deep Hope 4 Point Precaution Adoption Process Model which is described in Figure 5.1. (p.315)

The discussion will provide a basis for understanding the study conclusions which relate to hope, deep hope and trust which form the second aim of this study. These constructs are defined in Table 2.1 (p. 143).
The Deep Hope 4 Point Precaution Adoption Decision-Making Model represented in Figure 5.1 is a proposed new model of decision-making based on the Precaution Adoption Process Model of decision-making (Weinstein, 1988); that was modified to include Snyder (2002), Coulehan (2011) and Job (2007) and utilised as a theoretical framework in this study.

The researcher proposes that hope and trust influence the family decision-making process of organ donation that is motivated by deep hope. Time, as an indefinite period, is represented on the pink timeline which is dissected by the 4 decision-points which encompass the family decision-making process of deceased organ donation.
Each decision-point has an arrow connecting to a chronologically significant event for decision-makers. The decision-points comprise the:

1) autonomous decision-making stage
2) realisation that death is inevitable
3) organ donation decision
4) ongoing view of donation.

At each decision-point information and communication were interpreted through the participants’ lens of hope and trust, motivated by the deep hope that underpinned the decision. The most significant motivational influences associated with the chronological sequence of events are represented in the diagram. As mentioned in Chapter 2, the blue arrow in the figure represents the inexorable pressure of time as families come to the realisation that death and a donation decision are inevitable. The findings from this study revealed that each decision-making family experiences time differently to external observers, and so there is no scale to this timeline where time may ‘stand still’ and grief may be indefinite. The movement of ideas and barriers to donation are represented in the arrows circulating ideas of precaution and intention. Hope, trust and deep hope, are positioned according to their hierarchy of influence at each decision point. Deep hope was found to be most powerful influencer of the family decision-making process of deceased organ donation.

Decision-point one: pre-event attitudes and expectations: this point represents the ideas of donation and wishes regarding donation that are held by the deceased and their family. It is informed by information and communication within the family and community that influence the
individuals’ views towards organ donation, their trust and deep hopes for the future. The deceased’ wishes that were either recorded or known to the family held great importance in this study at this point, as did the mothers’ memories of conversations about organ donation.

**Decision point two:** Following the crisis event: the family were required to manage new information and communication related to the critical injury and impending death. *Hope*, in the form of prayers, miracles and mistaken diagnosis; and *deep hope* in the form of protection from suffering and recognition of life meaning, balanced with *trust* in negotiating the situation.

**Decision point three:** when the family discusses organ donation with health professionals: as previously mentioned this does generally not occur at a linear point in time, but instead may be interchangeable with *Decision point two* as decision-makers adjust to new information and draw their own conclusions. *Decision point three* is the time when the family become involved in discussion about organ donation with staff members. It was at this point that any perception of conflict of interest undermined trust and created barriers to organ donation. This study showed that *deep hope* drove many of the decisions at that point, and it was here that trust and hope faltered as the families made decisions to protect the dignity and meaning of their loved one.

**Decision point four** is the aftermath of the decision, when the memory of the experience and its ongoing implications become significant in the lives of the decision-making families. It is then that *deep hope* was affirmed through affirmation or acknowledgement; or lost to regret and despair.

*Hope, deep hope* and *trust* were shown to form valid frames to examine complex and emotionally charged family decisions. The analysis demonstrated that the constructs were pivotal
in all the family deceased organ donation decisions. This study confirmed that hope, deep hope and trust could be used to account for the deceased organ donation decisions made by participants. Further, the effect of competing dynamic influences on the behaviours of families could be explained at each of the four decision-points identified in the study by analysing the information and communication held within the participants’ narratives against the eclectic model.

Precaution became a significant barrier to donation at decision point three, the point when families discussed organ donation with health professionals. It was at this point that some families’ earlier trust in health professionals was undermined. New and unexpected information required families to undertake a significant cognitive effort to understand what they were being told. This was particularly difficult if they were unable to conceptualise the inevitability of death, or if the diagnosis of death and the organ donation process were not what they expected. Deep hope compelled some families to proceed with organ donation despite their sense of precaution and reservation. A loss of rational and relational trust related to ideas of conflict of interest, acted as a barrier to donation for other families.

The eclectic model presented in Chapter Two proved effective in explaining the family decision-making process of deceased organ donation in the early phases of the study. However, as the study progressed, and following further data collection and analysis, I noted that my original premise regarding the interplay of hope, deep hope and trust required modification. Analysis of the interview transcripts against the sequence of events and circumstances involved in each participants’ decision-making process, made it clear that deep hope was more influential
in shaping and influencing the families’ behaviours than I had initially anticipated. Further, the role of hope was variable, as levels of hope appeared to fluctuate significantly and frequently throughout the decision experience. A sense of hopelessness and signs of despair were also revealed at crucial points.

_Trust_ was less influential in shaping decision-makers responses to precaution and risk than I had anticipated. Following reflection and consideration of the literature, I posit that it may be that the Australian health care system engenders a high level of trust, and this possibly influenced families in this study. It is possible that this is an aberrant finding or context dependent and confined to this study. Most families appeared to be more deeply influenced by deep hope than trust when making their decisions, and deep hope underpinned all consent and most decline decisions. Therefore, to better represent the family decision-making process of deceased organ donation I have changed the positioning of hope, deep hope and trust in the proposed new model to more accurately represent the chronology of how the constructs influence the deceased organ donation decisions over time.

While one of the major findings of this study was the identification and analysis of the 4 point decision-making process, the model now requires further modification. I therefore recommend retaining Weinstein’s (1988) three stages of precaution, intention and decision, but applying the 4 points of decision-making to this model. I also recommend two changes to the structure of the model to better represent the influence of deep hope in the decision-making process experienced by families in this study.
First, at present the model assumes that the organ donation decision is generally made before the confirmation of death, an idea that is based on recent literature. This was found to be only partially true in this study. The positioning of the decision-makers recognition that their family member would not survive was of far greater significance in this study. This cognitive and emotional hurdle was a barrier to understanding and forward planning for decision-making. The families needed to be able to meet this next cognitive step to make sense of the question of organ donation. This was a critical point, where despair was balanced with hope, and subsequent evidence of deep hope in signs of families offering organ donation or making plans to honour the deceased by relieving them of perceived ongoing suffering. An unexpected observation noted in the analysis was that deep hope was a motivating factor for decision-makers that appears to precede trust for families negotiating ideas of fear and precaution in this model.

Second, this model is appropriate for families and individuals who hoped to help others at decision point one. Deep hope based on the knowledge of wishes made at decision point one drove decision-making for the families who utilised deep hope at decision point two and decision point three to create meaning that something good would arise from the situation. They hoped to trust the health professionals involved in the care of their family member, importantly, and they also hoped to trust the organ donation process.

It is proposed that the new model is suited to questions regarding organ donation, end of life care, or other situations of complex decision-making. However, a new study now needs to be conducted to examine the effectiveness of the new Deep Hope 4 Point Precaution Adoption
Decision Making Model and this will be discussed further in recommendations for further research.

5.2 Three major conclusions

There are three major conclusions arising from the findings of this study. The first major conclusion is that deceased organ donation decisions involve a process which evolves over time and consists of four key decision points. The second major conclusion is that the construction of hope, deep hope and trust influence donation decisions. The third major conclusion is that most families perceived organ donation required the sacrifice of peace at death. These conclusions address the purpose and aims of this study.

5.2.1 Conclusion One: Deceased organ donation decisions involve 4 key decision points

The first conclusion, which addresses the first aim of the study, is that deceased organ donation decision-making is not a singular or linear event, but rather an evolving process that occurs across a continuum of time. This study found that the decision-making process involves four key decision points and, depending on the circumstances surrounding the family members’ death, the 4 point process may not be sequential. These decision points do not only involve the actual organ donation decision, but comprise attitudes and experiences that help shape the families’ view of organ donation before and after their relative’s death. The key factors that influence family deceased organ donation decisions at each of the four decision points are information and communication.
Figure 5.2 presents the four decision-points and two major factors that influenced decision-making in this study. The pink horizontal arrow represents the continuum of time. The Precaution Adoption Process Model of decision-making (Weinstein, 1988), is based on a series of stages to reach a decision-point involving a continuum of time. In this study, each decision-maker at each decision-point, required sufficient information and communication to influence a positive cognitive shift sufficient to address fears of deceased organ donation, to enable consent to occur.

Figure 5.2. The 4 decision-points of the organ donation decision-making process and the major factors that influence each decision point.

5.2.2 Decision point one

A key factor that influenced family decisions in this study was the communication of information regarding the deceased persons’ willingness to be an organ donor. The families’ knowledge of their family members’ donation intentions at decision-point one was a major
influencing factor in family consent and refusal decisions, and is consistent with findings from previous studies (Siminoff et al., 2001; Thomas et al., 2009; Tymstra et al., 1992).

The findings from this study show that decision-point one takes place prior to the events leading to the death, and is positioned in the community environment. An individual, and sometimes their family, may make an organ donation consent or refusal decision encouraged by promotional strategies, media and public discourse, or a personal insight into the issues; or they may remain disengaged. This study found that prior to their deceased decision-making experience most families held attitudes and intentions that were supportive of deceased organ donation.

The families’ attitudes and views were influenced by a desire to help others, and were based on information regarding the benefits of transplantation. This study also identified that most families were aware that their deceased family member had either indicated an intention to donate, or had qualities which indicated they would be willing to donate their organs following their death. The findings in this study support previous studies that found community views of deceased organ donation are informed by attitudes and beliefs about death and organ donation, as well as by the individual’s knowledge, relationships, expectations, trust and hope for the future (Hyde, 2012; Walker et al., 2013; Siminoff, et al., 2013).

5.2.3 Decision point two

The findings from this study identified that a decision-point two occurs when families come to the realisation that their family members’ death is inevitable. This decision-point was
not fixed on the decision-making continuum, but could be seen to move between a period prior to the confirmation of death and discussion about death and donation with health professionals, to a period following the confirmation of death, after organ donation had been broached.

The study showed that it was only after families had been able to conceptualise the severity of the situation, and had reached a point of despair associated with the realisation that their family member’s death was inevitable, that they could begin to reconfigure their expectations. It was at this point that families began to consider a future without their family member. Their behaviours appeared to shift from hoping for their family member’s survival, to seeking to protect their family member from unnecessary suffering, and protecting their life meaning.

This cognitive shift was crucial in the decision making process. It marked a point where the focus of family attention shifted from the despair of realising that hopes for their family member’s survival were unfounded, to hope for their family survival in a new paradigm involving life without their relative. At this decision-point many families concluded that death was preferable to life in a ‘vegetative’ state, and this finding is consistent with other studies (Sanner, 2007; Sque et al., 2008; Siminoff et al., 2004).

Families who were witness to the events leading to the death, or who had proximity to their family member in the emergency setting appeared to reach this decision-point swiftly. They realised that death was inevitable and therefore accepted the diagnosis of impending death and its implications in similar time frames as the treating health professionals. Some families received
clear information about their family member’s condition which enabled them to have a realistic understanding of the dire prognosis. Families who had a clear understanding of the situation were less burdened by false hope because they knew that their family member could not survive and therefore, no hope of recovery. Having reached this point, most families emphasised that they did not want their family member to experience prolonged suffering. This finding is consistent with previous studies (La Spina et al., 1993; Sque & Payne, 1996; Bellali et al., 2007).

The families’ most pressing needs included information, proximity, compassion and support to gather at the hospital. These findings are also consistent with previous studies of family needs (Nelson, et al., 2010).

Families who had accepted the inevitability of death at decision-point two appeared to utilise deep hope (Coulehan, 2011) to sustain them. For example, some families offered to donate their loved ones’ organs with the desire to save life and to protect another family from experiencing a similar grief and suffering and to keep the memory of their loved one alive. The idea of transforming their tragedy into a positive outcome and honouring their family member was important to the families in this study. Similar findings have been reported in previous studies (MORI Research Unit, 1995; MacDonald, et al., 2008). The families who offered organ donation appeared to view their offer as intrinsic to protecting the dignity, meaning and memory of their family member.

Some families remembered decisions made at decision-point one and drew from that knowledge to inform their actions when they realised death was inevitable at decision-point two. The knowledge of their family members’ wishes about organ donation influenced the final organ...
donation decisions. It is important to note, that in this study this was not the most important factor that influenced the families’ decision. Jacoby and Jaccard (2010), and Sque et al. (2008) reported similar findings that show, a desire to protect their family member from perceived harm caused some families to over-ride the deceased’ wishes.

This study found that perceived threats to the family member or the family unit contributed to family distress and undermined earlier consent decisions. For example, some families were conflicted on one hand by their desire to honour their family members’ donation wishes, while conversely; they believed that they needed to protect the family member and the family unit from perceived harm.

In this study, it was important for families to know that death was inevitable before staff initiated organ donation discussions. Nonetheless, some families agreed to donate before the family had comprehended the severity of their family members’ injury and its ramifications. As a consequence, families grappled to understand the diagnosis, prognosis and the implications of their donation decision before the death was confirmed. For some families, this confusion led to perceptions of medical conflict of interest which threatened and reversed consent decisions. This contributed to family suffering during and after the decision-making experience. This finding affirms study findings from Sque et al. (2008) and Siminoff et al. (2013) who identified that families should have their understanding of the inevitability of the death assessed before health professionals raise organ donation.
This study found that trust was undermined on a rational and relational level when families became confused by new information or treatments that they could not understand. Families who had difficulty gaining access to their family member’s bedside and had insufficient information to understand that death was inevitable, developed the perception that their family member was primarily receiving treatment to enable organ donation. This view is a perceived barrier to organ donation that is held within the community and has been presented in other studies (Hyde et al., 2012; Morgan et al., 2008; Souter & Norman, 2010).

Families who saw or responded to the events which precipitated the death appeared to have a significantly better understanding of the futility of the situation than other families. The powerful influence that family witness to the events played on the families understanding of the situation cannot be understated. It became apparent that families were realistic about the prospects for their family member’s recovery when they received clear and accurate information regarding the mechanism and extent of the life threatening injury.

This study found that it was vital to allow families access and proximity to their dying family member in emergency care environments whilst being supported by compassionate staff. This access helps families to comprehend the information involved in knowing their relative is receiving treatment and for making deceased organ donation decisions when it is clear they will not survive. The families closely observed the way their dying family member was cared for and noted the quality of the communication by the attending doctors and nurses. The transparent witness of the situation enabled the family members to rapidly realise the prognosis was dire which allowed them to reframe their expectations. Importantly, this level of access and
transparency allowed the family to construct trust in the staff caring for their family member at this time.

In this study, the majority of the families either initiated a discussion about organ donation within the family or with nursing staff before the doctor had raised the question. This finding is similar to records which report 31% of organ donors’ families’ offered organ donation before being asked to donate (ANZOD, 2013). In this study, donation offers occurred only after families had reached decision-point 2 and were certain that death was inevitable.

5.2.4 Decision point three

The findings of this study demonstrate that decision-point three coincides with a discussion about organ donation between health professionals and the family either before, concurrently or after the family are informed of the death. In this study, families were directly influenced by health professionals regarding their expectations and understandings of the diagnosis of death and the processes of organ donation. At decision-point three, families expressed the need for 1) clear information about the un-survivability of the injury, 2) assurance that their family member was not suffering, 3) evidence of death, and4) timely, transparent information about the processes of organ donation. Importantly, families were adamant that they wanted assurance that their family member’s documented or undocumented wishes regarding organ donation were central to the health professionals’ organ donation discussions.

In most deaths, the treating doctor confirmed death and discussed organ donation with the family, which is consistent with contemporary Australian practices (ANZOD, 2013). It was
found that the doctors’ ability to sensitively discuss organ donation and the processes of
deceased organ donation either supported or hindered consent to donation at this decision-point.
Some families trust in the doctor and organ donation was undermined when they were asked to
donate by the treating doctor. This suggestion of conflict of interest was compounded if the
family perceived their dying or deceased family member’s wishes were irrelevant to the doctor.
Insensitive communication contributed to family distress and undermined trust to doctors and
nurses at this decision-point. Staff may have unwittingly influenced family decisions negatively
through insensitive communication, and several authors have identified similar findings
(Martinez et al., 2008; Sque, Long & Payne, 2005; Kesselring et al., 2007; Sanner, 2007).

This study found the discussion regarding their family member’s wishes was relevant to
the families in two ways. First, most families expected that staff would have used organisational
processes to confirm their family member’s wishes on the Australian Organ Donation Register.
This was important to most families who felt a strong sense of responsibility to ensure they
honoured their family member’s wishes, and did not want to make a mistake, which is consistent
with the literature (Pelletier, 1993; Sque et al., 2005; Martinez et al., 2008). Second, they wanted
to talk about their family member to ensure that staff knew that their loved one ‘meant
something’ and to share their memories. This has also been reported in the literature, and
according to Brooten et al. (2013), Sque; et al. (2008), and Lloyd-Williams et al. (2009) grieving
families benefit from talking about their family member and discussing and sharing their
memories with staff.
The registered organ donation wishes of the dying family member was checked only once in this study by the staff prior to discussing organ donation. On this occasion, the family immediately agreed to the donation request believing the information was correct but struggled to comprehend the situation. Most families indicated that donor register information was only discussed if the family specifically asked for the information. Two families who declined to donate argued that if their family member had wanted to donate they would have informed them and formally documented their decision. Studies have found that when the dying or deceased’ wishes are known, the information influences both family consent (Bellalli et al., 2007) and refusal decisions (Martinez et al., 2008; Verbal & Worth, 2012).

In this study the families were required to make organ donation decisions in circumstances where death was determined by the doctors who used circulatory as well as neurological criteria. In some deaths both sets of criteria appeared to have been used for the same patient, either before or after a family donation decision. The families were confused regarding communication related to the clinical signs of death. For example, the methods used to determine death, the visual indicators of death and the processes of organ donation created confusion for families as they were not what they envisaged. Evidence of this confusion was apparent when families who had sufficient knowledge to associate brain death testing with organ donation, voiced their concern that they did not see brain death confirmed before their family member became a donor, and they questioned the declaration of death. Instead, they described seeing clinical processes associated with DCD, and being unaware of DCD, had assumed that the tests to demonstrate brain death they had heard about were used to determine circulatory death.
Five families were involved in discussions with doctors about organ donation prior to the diagnosis of death, and 4 families discussed organ donation following the diagnosis. The families’ use and interpretations of terminology utilised by doctors and nurses when describing death, organ and tissue donation were poorly understood and used inappropriately and interchangeably without any realization that they had not understood the clinical situation. A similar finding has been reported previously (Curtis & Vincent, 2010). This misunderstanding had implications for the families’ understanding of what they had observed in the hospital.

Some families were frustrated because they could not understand what they witnessed, and were bewildered with their apparent failure to comprehend the differing contexts of death and organ donation processes- but this did not appear to influence their final decisions. Rodrigues-Arias, Tortosa, Burant, Aubert, Aulisio and Youngner (2013) also identified inconsistency and confusion evident in doctors’ understandings and interpretations of the determination of death in brain death and DCD contexts of organ donation.

While previous studies have identified families who do not understand brain death may decline to donate because they are fearful it will hasten or cause death (Franz, et al., 1997; Hyde et al., 2012), this was not a finding in this study. Rather, this study found that families understood that a diagnosis of brain death indicated their family member was irreversibly dead in person, and most families who came to that realization, were willing to donate their family members’ organs. Siminoff, Bur rant & Youngner, (2004) identified similar findings in a study which examined community views of death and organ donation. These authors found that while some individuals were confused in their understandings of the determination of death, others
indicated there was a point when the person was ‘as good as dead’ (p.2332), and able to donate, despite confusion regarding death. The understandings of brain death expressed by some families in this study were similar to those identified in studies of health professionals who were able to describe the physiological signs of brain death and tests for brain death, but still interacted with patients if they were alive after brain death had been confirmed (Pearson et al. (2001).

Significantly, family apprehension regarding the donation process centered on the perception that an organ donor would endure prolonged periods lasting several days waiting for surgery. These families perceived this delay as harmful to themselves and their family member and it became a barrier to donation. Families appeared to attribute harm to the idea that organ donation would prolong the dying of those who were not already dead, or harm the dignity and prolong the suffering of those who were deceased but ventilated, as well as their family. The dichotomy faced by families who knew their family member was dead and not suffering or capable of suffering, was balanced against the clearly articulated fear that their family member would continue to suffer whilst waiting for the donor transplant team. The genesis of the idea was drawn from their discussions with doctors. At decision-point three, families experienced difficulty in making decisions because they were uncertain of what to anticipate, or of knowing what was expected of them. Some families were offered or sought guidance, whereas others were unable to articulate their needs. Some families expressed distress because they felt they could not anticipate or plan ceremonies to farewell, and physically separate themselves from their family member. According to the participants, this was because they were ignorant of the hospital requirements for the body and the expected timeframes required for donation. This more nuanced finding regarding the information needs of families contributes to study findings that families of
dying patients seek information about end of life practices in critical care environments to help guide their decisions and expectations (Nelson et al., 2010).

Families responded in various ways to receiving new and unexpected information that did not meet their expectations regarding the care of their family member and the processes and requirements for organ donation. With new information, some families immediately reversed an earlier consent decision made at decision-point 2. Others withdrew from the discussion to take stock of the new information. Ultimately all families made a decision which they stated best reflected their family needs, to either agree or decline organ donation. This nonlinear progression of decision-making reveals the complex process of decision-making experienced by some families which evolves over time. In this study, some families reversed an initial decision to agree or to decline organ donation, while other families did this several times. This finding is consistent with previously reported findings; such as the study conducted by Walker, et al., (2013) and Martinez et al, (2008). It is significant in the Australian context, where records show that each year families withdraw their initial consent to donation (ANZOD, 2014) at decision-point 3.

5.2.5 Decision point four

It is important to reiterate that as previously mentioned, these decision-points did not simply involve the actual decision to donate or not to donate, but included attitudes and experiences which shaped the families ongoing view of organ donation after the family members death. Decision-point four represents the ongoing view of organ donation expressed by families in this study. It specifically represents the culmination of the families’ reflection on the events of
their donation decision experience and its consequences, and is entwined within the families’ ongoing bereavement experience.

Most families delayed reaching this decision-point because of their difficulty in obtaining transparent information. For example, families sought to understand the events surrounding the death, the care in the hospital and the processes of organ donation. Dissatisfaction increased over time if decision-makers remained confused about the events surrounding the death or the care that was provided to the deceased family member. Some families described their concerns regarding unanswered questions relating to the care of their family member. This information deficit appeared to increase discontent and have implications for most families who received minimal or no follow up information or support following their experience and appeared to complicate the family bereavement. La Spina (1993), Holtcamp (2002) and Sque & Payne (1996) reported that families seek information and support following the donation decision, and when unable to satisfy their information needs they may experience complicated bereavement.

Initially, the donor families in this study felt hopeful about their decision and its meaning. However, over time most donor families’ perceived that their decision to donate was not acknowledged or recognised by the organisations involved in the decision to the satisfaction of the families. This contributed to frustration and regrets for some families. For example, the families’ regrets primarily centred on unmet expectations regarding organ donation processes, which they did not understand, and which differed from information they had gleaned in the public discourse about organ donation. Some donor families sought to understand the benefit that their family members’ organ donation had conferred, and to affirm the meaning of their family
members’ life. Other donor families sought to justify their perceived sacrifice of allowing donation. The dissatisfaction that was expressed by families appeared to have been brought about by unmet expectations. Most families who had declined donation experienced ongoing disappointment or bewilderment regarding their decision-making experience. The family’ views of their experiences in the hospital and any related communication following the events appeared to inform the basis of their ongoing attitudes towards organ donation.

Ongoing attitudes towards organ donation were deeply influenced by the communication of information and appropriate acknowledgement of their experience. Families who did not have these needs met became disenfranchised regarding the processes of organ donation whether they had agreed or declined organ donation. Importantly, this study found that families who received support to create rituals associated with a peaceful death expressed satisfaction regarding their decision to donate at decision-point four, a finding which supports previous studies by Jacoby and Jaccard (2010), Martinez et al. (2008) and Vernale & Packard (1990). In this study, many families who had previously held strongly supportive views regarding organ donation said they had become disengaged as a result of their experience.

In contrast, donor families who received ongoing information about recipients and acknowledgement that the donation was appreciated, felt affirmed in their decision, and expressed a desire to encourage other families to make similar decisions by promoting organ donation. Martinez et al. (2008) and Sque et al. (2008) reported similar findings that families who received information about the recipients and benefits of the donation believed they had made the correct decision.
Most families in this study discussed their experiences and views of deceased organ donation and the organisations that facilitated and promoted donation within their family unit. Importantly, these families also indicated that their views of the organ donation experience had been communicated beyond their local circles of influence and into the wider community. An important finding from this study is that the decisions made at decision-point four may have ongoing implications for community trust in organ donation. For example, Hyde et al. (2012) and Verble and Worth (2012) suggested that the basis for the public mistrust for organ donation could be attributed to families relating their experiences and understandings to others in the community, and that these communications and information may add to community fears that donors are not deceased. This will be discussed further in the implications section of this chapter.

5.3 Conclusion two: hope, deep hope and trust, influence donation decisions

The second major conclusion in this study is that hope, deep hope and trust, played a significant role in the family decision-making process. This conclusion has major implications for clinical practices in end of life care, bereavement and transplantation outcomes, and addresses the first two aims of the study. The theoretical framework which has guided this study is based on the modified Precaution Adoption Process Model of decision making (Weinstein, 1988) and presents the premise that hope, deep hope and trust underpin organ donation decisions, an argument which is supported by the findings in this study.

Deep hope appeared to drive both donation consent and refusal decisions. Families who agreed to donation hoped that other families would be protected from grief and that some good could come from their tragedy. These hopes and intentions that were formed at decision-point
one ultimately contributed to decisions made at decision-point four. The decisions were dependent on families’ interpretations of trust and affirmation of their hopes and expectations. Figure 5.3 builds on Figure 5.2, the 4 major decision-points of deceased organ donation across time, to describe the influence of hope, deep hope, and trust and the ideas relating to intention and precaution in decision making (Weinstein, 1988). In this study each decision-point involved a process in which families interpreted the perceived risks of deceased organ donation using available information and communication, which then influenced a cognitive shift which led to a decision. In this diagram I have indicated that these risks are interpreted through families’ conceptions of hope, deep hope, underpinned by the influence of trust.
Figure 5.3 The 4 major decision points of deceased organ donation across time, hope (Snyder, 2002), deep hope (Coulehan, 2011), and trust (Job, 2007) and intention and precaution in decision making (Weinstein, 1988).

As discussed in Chapter 2, the interaction between Weinstein’ (1988) Precaution Adoption Process of decision making and the role of deep hope, hope and trust forms the basis of the theoretical framework utilised in this study discussed previously in this chapter.

5.3.1 The role of hope

This study found that the donation decisions within the family appeared to be strongly influenced by mothers of the deceased, other female mother figures, or their representatives. In most decisions, the mothers of the deceased appeared more aware of their family members’
donation intentions than other family members. They reflected on conversations and behaviours which they believed supported their views regarding the family members’ intentions, and these views were supported by other family members. The families’ construction of hope appeared deeply seated in the mothers’ memories of these moments. As previously mentioned and according to the literature, when a family knows their family member’s donation intention, they will generally honour the consent or refusal decision (Walker, et al., 2013). However, the literature does not identify which family members are more likely to be aware of the family members’ views so this is a significant finding in this study.

This study found that donation decisions were motivated by the families’ hope to find meaning from the death, and the deep hope to protect the identity, dignity and life meaning of the family member. The families held deep hopes that their family member would have a peaceful, dignified death and be remembered well. This deep hope influenced family decisions at each decision-point. The donation intentions of the deceased family member expressed at decision-point one, influenced the formation of hope and deep hope in the subsequent family donation decisions. Deep hope inspired some families to offer donation when they became aware that death was inevitable at decision-point two.

In several decisions, despite adversity, deep hope which was based in the family knowledge of their loved ones’ intention to donate their organs, sustained families as they experienced unexpected barriers to their donation decision at decision-point three. The finding that many families in this study were searching for information about the organ donation process in advance of being asked to donate is an indicator of how deep hope can drive decision-makers’
behaviours. This specifically relates to evidence from two deaths, where the families offered organ donation. Further, the role of deep hope at decision-point three is contextually significant to practice, because the families believed they would not have been asked to donate or been involved in a decision about organ donation if they had not offered to donate. This was because the families perceived that staff members were taken by surprise when the families initiated the organ donation discussion.

Trust played an important role in the formation of hope for families, who sought to have their trust in health care providers at decision-point 1 affirmed, and actively sought to protect their family members’ body and person from harm at decision-points two, three and four. Previous studies by Morgan (2008) and Hyde et al. (2012) identified that trust plays an important role in influencing community attitudes regarding organ donation. Verhaeghe et al. (2007) identified the role of trust in the formation of hope for families of critically brain injured patients when families start to understand the significance of the events at decision-point two. Exley, et al. (2002) identified that trust is a feature of decision making which correlates with decision-point three, in this study, and is further supported by Sque et al. (2008). Verbal and Worth (2012) suggested that dissatisfied and satisfied families influence those within their communities regarding deceased organ donation decision making which coincides with decision-point four in this study.

5.3.2 The role of deep hope

The mothers in this study appeared to carry this responsibility as a part of their perceived role of protectors of their family members’ needs and best interests. The mothers sought to
protect their family member from perceived threats which included their family members’ life meaning and memory and this finding has been previously reported in the literature (Sanner, 2007; Sque, et al., 2008; Exely et al., 2002). As previously mentioned, this study has identified that the mother was a major influencer of the decision-making process and outcome of all consent decisions. Further, of the four refusal decisions, two decisions appeared to be primarily influenced by the mother of the deceased, a third was decided in isolation by the deceased’ husband, and the fourth refusal was made after the deceased’ wife withdrew a donation offer. This finding also addresses the first aim of the study which was to identify the major influencers of the deceased organ donation decisions.

There is scant discussion regarding the role of ‘mothers’ as the major influencers of family deceased organ donation decisions in the organ donation literature. However, as mentioned in Chapter 2, gender appears to play a role in decision making at decision-point 1 with Woolcott (2012) finding that 68% of woman had made a donation decision compared with 59% of males. It is also possible that because women live longer, they may be over-represented as a demographic group.

Although not specific to the mother, the role of the parent in organ donation decision-making was examined by Moraes and Massarollo (2008), who found that parents were more likely to decline to donate than other relatives of the deceased. In contrast, other studies have found that parents are more likely to agree to donation (MORI Research Unit, 1997) and mothers have been identified as being highly represented in donor family studies (Bartucci, 1987). While this study showed that females played a significant role in influencing the family decision, most
families also described a collaborative decision-making effort and viewed their decision as a family response. Importantly, in most instances the families’ decision, at decision-point three, was described by the families as being presented to the treating physician by the mother of the family member or her representative. It is possible that the role of females or the mother as an influencer of donation decisions may be culturally specific and this will be discussed later in this chapter as a recommendation for further research.

5.3.3 The role of trust

Australian organ donation guidelines recommend that the treating intensive care specialists should formally request organ donation from the dying or deceased patients’ family. The practice generally follows a decision to withhold or withdraw treatment following proof of brain death or when it is recognised that continuing life sustaining therapies are not in the patient’s best interests (ANZICS, 2013). These decisions generally follow at least one to two days of treatment within the ICU. In practice this enables the health care professionals to build a relationship with the family (ANZOD, 2013). In this study four families described their discussions with the intensive care specialists regarding organ donation and of those families, two families agreed and two families declined donation. According to the families, the quality of the relationship constructed between the family and the requesting doctor influenced their experience and decisions at decision points two, three and four. In this study, the treating doctors comprising specialist, intensive care and emergency physicians either requested organ donation or responded to offers of organ donation from the family.
This study found that emergency department staff played an important role in assessing the dying patient and forming a relationship with the families as they gathered at the hospital. The time frames involved in the emergency department extended from approximately 3-6 hours. The emergency physicians set the family expectations regarding the criticality of the situation. The finding that emergency specialists obtained a 100% consent rate to donation from families after explaining that their family members’ condition was un-survivable was unexpected. It is however, consistent with findings of high levels of consent to the request to donate organs in emergency departments as compared with the ICU context (Rady, et al., 2010) and will be discussed further in this chapter.

The finding that the early trusting relationships between the emergency staff and the families were undermined by staff changes when personnel went off shift or handed over to intensive care staff was significant. These findings reveal how communication gaps may cause a loss of the relational trust that has formed between the family of the dying patient and the staff who are providing direct care to their family member. If the family are unable to rapidly establish new and trusting relationships with staff members who take over the care of their family member, it is likely that an inability to understand the care that is given to the family member or confusion about the goals of care may develop within the family.

Evidence of the importance of trusting relationships between the doctors and decision-makers was seen when the families offered organ donation. It became clear in this study that health care professionals need to know how and when to respond to the offer of donation when it is presented to them by families of dying patients. The staff response to the offer of donation
appeared to have a similar level of importance as the family perceptions of communication when organ donation is requested. In this study and according to the families, their offers of donation received an ad-hoc response which caused them surprise.

Family trust in the health professionals involved in the organ donation discussions and their associated organisations, was undermined if staff did not demonstrate an overt patient centred focus throughout the decision making process. The response to the donation request at **decision-point three** was influenced by the presence of rational and relational trust between the family and the doctor. The families trust was affirmed when they were given timely, accurate and transparent information that was communicated with compassion. Verhaeghe et al. (2007b) conducted a study of patients’ families in critical care environments which found that the criterion for trust is accurate information provided in an empathetic manner. When a trusting relationship formed between the family and the staff, it appeared to foster the growth of **hope** and **deep hope**. Studies have shown that family trust in the doctor who requests organ donation contributes to consent decisions (Kesselring, et al., 2007; Martinez, et al., 2008). The finding that treating physicians played a significant role in providing information and in communicating about death and the organ donation process and influenced some families decisions has important implications for practice and will be discussed further in this chapter.

This study found that nurses to a lesser degree also influenced family **trust**, and the family decision-making experience in both positive and negative ways. Some nursing staff were described warmly for communicating information regarding organ donation to families who had arrived at **decision-point two** in advance of their discussions with doctors. These families sought
information from nurses who they described as being accessible and approachable. The findings from this study support the view of Pelletier (1993) that communication between nurses and families regarding organ donation may influence families to consent.

Most families in this study were unfamiliar with the role nurses play in organ donation coordination until after donation consent. The family met the donation nursing staff following decision-point three when donation nursing staff interviewed the family and provided them with additional detailed information regarding the organ donation process and its requirements. A significant finding from this study is that families were required to make donation decisions without receiving sufficient information about the processes of organ donation. This finding implies that some family consent and refusal decisions may not have met the family expectations of informed consent and this will be discussed further in this chapter.

In this study, the families described their experiences and interpretations of events using complex interpretations of time which included ideas such as time standing still, and time as suffering. These interpretations appeared to contribute to family distrust in donation processes. This distrust was significant for some families and contributed to a loss of hope and organ donation refusals. Time was interpreted in different ways by different families. Most families appeared to associate delays in receiving information about organ donation and perceptions of delays in arranging organ donation with increasing distrust. As previously mentioned, delays in arranging organ donation influenced refusals in this study, and is consistent with other studies (MacDonald et al., 2007).
Although donor family studies have previously identified that delays in donation surgery contributed to family distress and were an area requiring improvement, the extent of this perceived barrier appears unique to contemporary Australia (Neate et al., 2013; Thomas, et al., 2010). In this study the families’ apparent fear of donation processes when overturning prior consent decisions was not due to a fear of the surgical process, but rather the fear of the harm associated with the surgical delay to the dying family member and their family. This is a significant finding that has not been reported in the previous research. Another important and related finding from this study was that the organ donation practice of transporting brain dead patients to surgery with a beating heart is a barrier to consent for donation and is consistent with the literature (MORI Research Unit, 1995).

Some families spoke about the arbitrary nature with which the time of death was recorded, and some families appeared to interpret that the declaration of brain death was not so much about a declaration of the death of their family member, but rather a legal and organisational convenience to enable the cessation of treatment and organ donation. This view appeared to contribute to ideas of mistrust regarding the processes of organ donation and has previously been reported in the literature (Souter & Van Norman, 2010; Sque et al., 2008).

The findings from this study support previous studies that have found some families need time to consider organ donation and its implications before making a decision (Jaccard & Jacoby, 2010). This has been identified as being beneficial because it allows families to come to terms with the situation whilst at the same time gathering information which enables them to be better prepared for a response. According to Bellali, Papazoglou and Papadatou, (2007) and
Martinez et al. (2008) this practice is associated with increased family consent to deceased organ donation. Coulehan, (2011) suggests that the palliative care approach of ‘hoping for the best, but preparing for the worst’ (p.145) allows an individual to manage information and reconceptualise hope and deep hope. This approach may be especially relevant in contexts of organ donation decision-making where unexpected life threatening events of critical illness or injury suggest a high probability of death occurring. Therefore, care plans should consider the possibility that if treatment is unsuccessful, the end of life care needs and wishes of the individual are identified, and if death becomes inevitable, they become integrated into the delivery of care. This approach would allow more time for the families to adjust to the circumstances and to seek and receive the information and support they require and this will be discussed further in this chapter.

Most families in this study assumed their family member would not survive when given unambiguous information. The idea of decoupling the information, previously mentioned in Chapter 2, that is, separating the discussion regarding the patients’ un-survivable condition from discussions about organ donation was important for the formation of trust for families in this study. This was a significant finding in this study and will be discussed further in this chapter. Importantly, when the majority of families were informed that their family members’ condition was ‘un-survivable’, the idea was clearly understood by all the families.

In contrast, when terms such as ‘brain dead’ were used by staff to indicate irrevocable injury, the meaning became ambiguous for some families, who despite recognising the irreversibility of the condition, became confused about its implications for their loved one. This was because the information that was communicated by the doctor at the time of discussion
about brain death varied from the families understanding of brain death. Some families found that this new information created doubts regarding the irreversibility of their loved ones condition and their capacity to feel pain which led to confusion and undermined trust.

The physiological context of the death and organ donation decision-making process involved significant trust implications. Families did not appear to understand the options and implications of DCD compared with DBD decisions. The families who agreed to DCD did not appear to be aware at the time of their decision that the practices involved in DCD limited the number of organs that could be donated, and precluded the donation of the heart. These constraints were poorly understood and had the potential to significantly affect the family levels of trust, and deep hope. The implications of this lack of transparency may also affect those awaiting transplantation, and those who agree to donation. One family when seeking more information about their donation experience at decision point 4 conducted an internet search about the process of donation after cardiac death. They were disappointed to find that if they had understood the situation better and the possibilities regarding organ donation, they may have chosen to wait until their family member became brain dead because that would have enabled beating heart organ donation. This information was not understood at the time of the decision. When the family confirmed this information with the organ donation organisation, the knowledge contributed particularly to the mother’s distress because her hope for another person to benefit from the beating heart was not realised.

The relationship of trust between the staff who asked for consent and the decision-maker members was undermined when words such as ‘harvest’ were used to describe organ donation
practices. According to several families, the use of this terminology decreased their intention to donate and contributed to their distress. These barriers have been previously identified in the literature (Fulton et al., 2002; Morton & Leonard, 1979; Sque et al, 2008) and remain barriers today. Factors that negatively influenced the decision to consent to donation included insensitive terminology, ideas of being a ‘guinea pig’ and descriptions of the individual body parts and dissection processes required for organ and tissue donation that were presented by health professionals in interviews with the families.

The interviews in which written consent was sought for a list of different body parts contributed to a sense of despair for some donor families, and is consistent with reported findings (Thomas et al., 2009). Other behaviours which families viewed as organ centred included signs stating *maintenance* hanging on the bed of their deceased loved one whilst the deceased’ body was continuing to receive ventilatory support whilst awaiting organ donation surgery. These practices were perceived as harmful, contributed a loss of hope, a loss of deep hope and distrust for the families and contributed to families declining to donate.

*Trust* was enhanced when families were given transparent information regarding the transplantation outcomes of their organ donation. The idea of restricted donation, with ‘nothing on the outside’ was evident for some families in this study who were concerned that eye tissue could be taken without their consent. Families revealed some fears that organ donation could mutilate or harm their family member which is consistent with previous studies (Bauchner, 2001; Bray, 2006; Haddow, 2005).
Deep distrust in the organisational processes associated with organ donation was expressed by two families who were fearful that if a family consented to donation, their decision would allow the body to be effectively ‘ransacked’ for useful organs and tissues. This fear was particularly revealed by families who had provided consent to organ donation before understanding the un-survivable nature of their family members’ injuries, and without receiving sufficient information to understand what their agreement to organ donation involved for their dying family member.

5.4 Conclusion three: most families perceived organ donation required the sacrifice of peace at death

The third major conclusion addresses the third aim of this study, which was to identify if families were content with their decision making experience. The families who agreed to organ donation and those who declined had similar clinical experiences, events and challenges relating to the impending death of their family member. All the families in this study affirmed that the organ donation discussion was appropriate in the context of death and end of life decision-making, and is consistent with previous studies (Pelletier, 1993; Chapman, et al., 1995; Sque 2013). This study found that while most families had regrets about being unprepared for the decision-making experience, they believed they had made the correct decision in the circumstances.

Importantly, this study found that most families described finding the decision-making process a difficult experience during which they encountered new and sometimes bewildering information with unanticipated meanings. This led to decisions which did not always reflect the
deceased wishes or provide comfort to the families. According to some families, the experience had contributed to avoidable suffering for the family. Families felt ill-equipped to manage the requirements of organ donation whilst trying to navigate a peaceful death and farewell for their family member. Further, the families were not ready to conceptualise the process of separating from the body, and were unprepared for the processes of organ donation, or the experience of end of life care in this context of death. Similar findings have been reported previously in the literature (Jacoby & Jaccard, 2010; Pearson et al., 1998; Thomas et al 2009).

The primary factor that families described as obstructing their consent to organ donation, was their angst caused by what they perceived as dehumanising intensive care practices related to organ donation. The perception that there would be prolonged delays in arranging organ donation contributed to this view. Further, many families described organ centred behaviours plus a lack of empathy from the staff that caused them distress. Some families described staff as appearing to focus on completing the required documentation, and ‘ticking boxes’ that centred on the deceased’ organs rather than caring about the qualities, or meaning the person held for their family. These practices were perceived by the families as removing humanity from the situation and other studies have reported similar findings (Pearson et al., 1995; Thomas, et al, 2009). For example, Thomas et al.(2009) reported that families found the technical nature of the consent process as difficult, with one family stating it was ‘horrendous’ (p.591).

Furthermore, an inability to engage in therapeutic relationships with the staff was described as damaging for some families. Some families expressed anguish that some nurses and donation staff had not provided information and support. These families spoke of needing help
and wanting someone to reach out to help them and their family. According to the majority of participants, a lack of compassion, perceptions of conflict of interest, and insensitive or dehumanising practices negatively influenced their views and decisions.

In this study, families who had their trust and hope needs met and were content with their experience and decisions were in the minority. Some families described receiving support at the bedside which helped them through their decision experience. However, many families did not have this experience and spoke of how it was difficult to be at the hospital feeling alienated and disconnected from both the nursing and medical staff. These families described being unable to understand the situation and the care. Unlike satisfied families, families who expressed dissatisfaction with their experience spoke about a paucity of transparent public information about the organ donation process. These families argued that transparent information would have assisted them during their experiences, and importantly, may have enabled them to make consent decisions.

The families in this study were unified in their view that transparent information should be made available at decision-point one, regarding what families should expect when agreeing to deceased organ donation. Families were keen to know, who or what was involved in the donation processes, what organs were taken and if they had any choice in these decisions. Families wanted to understand their role and how they would farewell and honour their family member. They sought guidance about their responsibilities, and questioned how and when their family member’s interests and donation decision was considered. Families expressed a need to know what to anticipate, and to understand, how and when their family member’s body would be taken
away. Finally, they wanted to know how the donation would be acknowledged and if, and when, they would meet or communicate with the recipients.

Most families had to work harder to rationalize what they were hearing and seeing following their agreement to donate. As their confusion increased, their fear also increased. This information and compassion deficit appeared to contribute to additional fatigue, anger and suffering. Some families, who had originally agreed to donate, changed their minds and vacillated, making efforts to balance their perceived threats. In contrast, other families felt impotent, and were unable to voice their distress. Hence, the families were of the view that they were required to sacrifice peace at death, and received little follow-up care or affirmation for their decision and perceived sacrifice. Clearly, families who had their family members and their own needs met also sacrificed in some ways, however, that sacrifice was more clearly balanced for the family against the good that was achieved.

The families were strongly of the view that their donation had been a conscious giving away of their loved one to help others. The difficulty for all the participants was that even if they had a previously held positive views towards organ donation and had themselves been committed to organ donation, they had insufficient information to prepare for the experience, decision and outcomes. Families would have preferred transparent information about the organ donation process before the events, coupled with proactive compassionate support and guidance to help them throughout their experience. Some respondents suggested that their experience had led them to feel they were tricked into signing organ donation registration without receiving
sufficient information to make an informed decision, which therefore undermined their trust in organ donation processes.

Many of the families in this study relied on their previous professional knowledge or friends, relatives and colleagues’ professional knowledge of biology and medicine, law and nursing to understand the processes of organ donation and when pondering what would happen next in their experience. They resented not being forewarned regarding what to expect if they agreed to their family members’ donation, or the consequences of their decision. They suggested this information should be available publicly on organ donation websites, through school education programs or associated with drivers education programs. Most families argued that this transparency would eliminate the need to guess or imagine the processes which led to the perpetuation of myths. They believed this information would also allow the community to better prepare themselves for the process requirements realising that these were normal and expected.

5.5 Implications for policy and practice

There are a number of implications which emerge from this study, and they particularly pertain to improving communication regarding organ donation processes and practices, and in the delivery of end of life care in critical care environments. These improvements could be effectively applied to each of the 4 points of decision making presented in this chapter. If the information and communication barriers to consent to donation identified in this study are addressed in policy and practice, it would be possible to significantly increase the rates of consent to organ donation in Australia in line with international benchmark statistics. The public discourse in Australia suggests that once a family is aware of their family members desire to
donate it is simply a matter of respecting that intention. As this study has found, this is not the case. The community expectation regarding organ donation processes and the clinical reality differ. First, the public discourse is not underpinned by transparent, accurate accessible information. Second and as this study has shown, there are organizational barriers to organ donation and a range of modifiable factors in the decision-making process which make it difficult for families to consent to donation.

Over the years organisational practices and activities associated with organ donation by health care professionals have been framed by regulation, protocols and power structures which have enabled some workplace cultures to evolve in health care practices involving end of life care and organ donation which diminish trust for families and staff who are involved in organ donation practices. The medical ownership of death and organ donation discussions has contributed to a further erosion of trust when relationships established between patients’ families, doctors and nurses are undermined. A further problem is ‘siloing’ of communication between the health care team that further contributes to a lack of transparency and distrust.

It is evident that some workplace cultures have developed in hospitals that divest humanity from the relationships, clinical environment, meaning and future for patients and their families involved in donation decision making. Strong evidence from this study shows that exceptional person and family centred end of life care was demonstrated for one family and this points to the possibility that improvement is achievable within existing arrangements. Despite this, the results from this study suggest that there remains much scope for improvement in the Australian context.
Strategies to help health care professionals forge a trusting rapport between the patient and the family will contribute in two ways. First, at an individual level for the family who are faced with a death and an organ donation decision; and second, at a community level where the idea of public trust in organ donation processes may be undermined by media, poor clinical practices and poor communication. This lack of transparency contributes to public fears that the needs of recipients will trump the needs of dying patients if the dying patient is registered as an organ donor (Hyde et al., 2012; Morten et al., 2008).

In order to increase organ donation for transplantation consent and public confidence in deceased organ donation, it is important to align family and community information needs and expectations with clear, accessible information regarding organ donation processes which is compassionately delivered by clinical staff and is available to the public. This will create transparency and help to build trust. This trust will be further affirmed by the removal of perceptions of medical conflict of interest. This can be achieved by 1) providing clear information to those who request organ donation, and 2) ensuring care and approach is person and family centred by ensuring the dying family members’ wishes are central to the decision-making process. The following section will identify the implications and recommendations that relate to the specific decision points previously presented in the Deep Hope 4 Point Precaution Adoption Process Decision-Making Model (Figure 5.1, p. 315).

5.5.1 Implication and recommendation for policy at decision-points 1, 2, 3 & 4:
the influence of female decision-makers
The implications that arise from this study shows that family decisions were most influenced by the mother or female mother figures and this has significant implications for policies regarding the approach and management of organ donation education, requests and management. Decisions were most influenced by being assured that the wellbeing and wishes of the dying family member were central to the care practices of the staff.

First, policy makers should review and improve communication, education and support strategies utilised at decision-points 1, 2, 3 and 4. At decision-point 1, the findings showed that when families were not given a record of the deceased wishes, some assumed that their loved one did not want to donate. This is a significant barrier for organ donation which is not present in countries such as Spain as it does not utilise a donation register but rather focuses on organisational processes within hospitals to maximise family consent (Dominguez-Gil et al., 2010).

The focus on securing donation at only decision-point one is unbalanced because it requires equivalent efforts at all the decision points to result in increased donation consent. The significant costs and efforts associated with focusing on securing donations at decision-point one only have resulted in a decision-making structure which confines donation consent to overtly positive members of the public who are provided with minimal information about the organ donation process and therefore make assumptions about what is involved. The policy that encourages the promotion of organ donation in association with an organ donation register has set a belief amongst members of the public that consent to donation is confined to documented consent registrations. This unbalanced approach gives rise to the belief that grieving families are
the primary barrier to best practice in organ donation consent in Australia but this study shows that this is not the situation.

Policies relating to end of life care in hospitals need to be addressed. Most families in this study expected staff to have identified the wishes of the dying or deceased family member from organ donation registers before discussing organ donation with their families and they also expected that staff would have provided this information to them as part of normal end of life care. Such a practice would alleviate the pressure and sense of responsibility experienced by the families, and particularly the ‘mothers’ who sought to make the right decision for their family member whilst suffering the physical and emotional effects of shock and grief.

In Australia, it is already a policy expectation that this information should be accessed. The information is readily accessible to health professionals using a 24 hour telephone service however, health organisations need to be accountable for utilising this information appropriately. I therefore recommend that the policy should be enforced, that retrieving this information should be standard practice in all health care facilities, and health professionals should be required to bring this information to the end of life discussion with the family.

A related recommendation is that there should be ongoing education and audit for health professionals regarding the appropriate use of this information, to ensure the registered information is utilised at the time of death for organ and tissue donation decisions. An additional recommendation is that the doctor who discusses death needs to present sufficient and transparent information to the decision-maker so they know that their family members’ best
interests are protected, and that the confirmation of death is rigorously attended to by qualified specialists.

Individuals wishing to register their donation wishes should be provided with accessible, transparent information about the process of organ donation thus enabling a more informed consent or refusal decision. These documented wishes should be provided to the family at the time of death similarly to the provision of information held within a will, to support decision making. Trust in the organ donation processes and their governance is undermined when families follow the advertised requirements to be a donor and then find that their wishes are ignored. Therefore, the community expectation that registered donation wishes will be utilised in decision-making must be addressed for every death where a health professional is involved in caring for a deceased and their decision-maker.

If these issues are not addressed, the policies which support public awareness campaigns regarding organ donation and the organ donation register should be ceased because community trust is undermined when the information is not used effectively. This recommendation aligns with legal, ethical, professional and community standards and expectations and should be included in quality review measures.

5.5.2 Implications for policy at decision point: 3 & 4: Surgical delay and dehumanising practices

A national organisational review should be conducted of clinical organ donation policies, guidelines and processes to address dehumanising practices and real and perceived time and
location barriers to donation. As this study has shown, policies that decrease the prolonged time frames required for donation to proceed would benefit the dying patient, their family and recipients. The organ donation process should be streamlined to minimise the delays between a decision to donate and the transfer to surgery. Time delays in clinical and legal processes should be addressed, and staff involved in supporting the family and the potential organ donor should be informed of expected time frames for the donation process so that appropriate support can be arranged for the grieving family.

Refusals brought about by long delays spent waiting for donation surgery is an important modifiable factor that can be addressed through quality improvement processes. Improved efficiency in facilitating organ donation surgery is likely to have significant cost and resource implications for the use of limited intensive care resources. Australian audit data of family refusals for the period January to March 2014 indicated that 5% of decision-maker refusals were attributed to families being unprepared to wait for the anticipated period expected for organ donation to be arranged (Organ & Tissue Donation Authority, 2014, p.22).

It is therefore recommended that strategies to address real and perceived delays in facilitating organ donation surgery are addressed. This can be achieved by providing specific organ retrieval teams to ensure that organs are not declined for ‘logistical reasons’ or consent withdrawn because it was perceived by the family that it would take too long. In this study, delays in surgery inhibited consent, contributed to prolonged family suffering, and had the potential to render the offered organs un-usable because of the death of the organs associated with difficulty in maintaining a deceased patients’ organ function. In Australia, the teams who
perform the organ recovery are often the same surgical team that implant the organs in the recipient. The surgical team is often required to juggle their normal case load with their on-call availability for organ donation.

It is therefore recommended that specialty staff and equipment should be available to provide an immediate response to these complex situations in both metropolitan and regional locations. This would help minimise the extended timeframes required to arrange organ donation. This strategy would also enable expert staff to respond to the situation, to communicate and facilitate donation and potentially increase the number of donors and transplantable organs. Furthermore, the efficient and consistent use of technology to increase efficiency and to reduce delays should be introduced into Australia. These practices have been utilised over decades Europe and North America for renal transplantation as they lead to increased utilisation of organs and their successful transplantation. More recently these technologies been effectively utilised for lung and heart transplantation (Daily Mail, 2014). There are significant cost implications attached to these strategies, however, the benefits of increased transplantation will contribute to savings over time.

5.5.3 Implication for policy at decision-points 1, 3 & 4:

Perceptions of medical conflict of interest

In Australia, while the organs are surgically removed by a team of transplant surgeons who are not involved in treating the patient, donation is generally sought by the doctor of the dying patient who when unsuccessful in saving the patient’s life may then request organ donation (ANZICS 2013). In this study this practice contributed to angst for families, particularly if they
had difficulty in forming a rapport with the treating doctor, or if they questioned the treatment or quality of the care provided before the death. Previous studies support the idea that families of adult patients are more likely to distrust a request for donation that comes from the doctor treating their family member (Martinez, et al., 2008) whereas they may be more willing to accept the request from a separate health professional using a decoupled approach (Gortmaker et al., 1998) as mentioned in Chapter 2.

The countries that are most successful in obtaining consent for organ donation such as Spain, Portugal and the United States use health professionals other than the treating doctor to request organ donation (Traino & Siminoff, 2013). Therefore, this study recommends that the policy should be reviewed to align Australian practices to meet the legal and ethical principles of separation of interests, to support clinical practice that enables one team, who provides care to the patient and their family. Once they believe that the patient will not survive they should advise the family.

Once the decision-maker understands that death is inevitable, a separate team of appropriately skilled health professionals should be utilised to discuss organ and tissue donation with the family. This clearly defined process provides greater assurance to the family, witnesses, health professionals and the community that the dying persons’ interests are protected. This role separation, or de-coupling, will help remove perceptions of conflict of interest. It will also help to build relational trust and continuity of care for families who are exposed to multiple staff across different settings in the hospital.
5.5.4 Implication for policy at decision-point: 1, 3 & 4: Communication

This study shows that information and terminology used in communicating about organ and tissue donation is poorly understood, and often used inappropriately in communication about donation decisions by the community, policy makers, health care professionals and decision-makers. This has implications for families who have limited understanding of what organ donation processes entail and the implications of their refusals and consents. Most families in this study based their decisions on assumptions about organ and tissue donation because they were not provided with clear information. As a result, this failure to understand or receive correct information contributed to unnecessary suffering for the families in this study and may have contributed to refusals.

It is essential that health care practitioners and policy makers clearly define and ensure consistent use of accurate and transparent organ and tissue donation terminology, and ensure that all written communication is made clear at a micro, meso and macro level. The Institute of Medicine (2006), ANZICS (2013) and other bodies have concluded that health professionals should be sensitive to the needs of families when conversing about organ donation professionally and publicly. Specific words have been identified as contributing to family distress and donation refusals. As discussed in Chapter Two, the word harvest is recognised as an offensive term, and some families in this study declined donation following the use of this term.

Therefore, I recommend that professional organisations, policy makers, educators and communicators should rectify the situation by ensuring that staff use language which meets community standards and the ethical standard of ‘Primum non nocere’ ‘Above all [or first] do no
harm’ (Beauchamp & Childress, 2009, p.149). This can be achieved by conducting a national review of the terminology used in healthcare facilities. Following the review, communication guidelines that better reflect contemporary community standards for discussing death and organ donation processes can be developed and implemented utilising a national education program for health care professionals.

5.5.6 Implication for practice at decision-point: 1, 2, 3 & 4: End of life care

The finding in this study that there are 4 key decision-points in the family decision-making process which can be anticipated by assessing the families experience and understanding of pre-hospital events, presents the possibility of a more nuanced approach to working with families of the critically ill. This may be particularly relevant when the family is already complicit in the care of their relative, and may potentially carry a burden of guilt, anxiety or fear related to their role of being either present as a first responder or for failing to prevent the event. The families own efforts to prevent the injury may also potentially influence their appreciation that the condition is un-survivable. This is particularly relevant in complex situations where family understandings of dying or deceased persons’ wishes and best interests are pertinent to end of life decisions. This may be particularly germane in the context of traumatic death and suicide where evidence suggests some families are more willing to agree to donation (Exley, et al., 2002; Siminoff, 2001).

Families in this study found that early discussions between themselves and health professionals about the criticality of the situation enabled them to conceptualise the possibility that death was impending and prepare for the death. The families’ also recommended that critical
care staff should anticipate that a family may recognise their family member’s condition is un-
survivable early in the admission. In these circumstances the family may wish to ensure that
donation is discussed and arranged as quickly as possible for two reasons. First, because the
family may wish to limit any perception of their family member suffering, and second, by
staying in the environment the family may experience further suffering. On many occasions this
contributed to additional distress for the families.

Families require proactive support in planning the rituals and ceremonies of end of life
care, which are commonplace in good palliative care practice in Australia. This study found that
it is pertinent and relevant to consider the dying patients’ end of life decisions. Families’ needed
to understand what to expect when organ donation took place in situations of DCD as well as
DBD processes and to plan their remaining time with their family member in a manner that was
peaceful and dignified. Health care professionals have an obligation to present the decision-
maker with the range of options appropriate to their context of decision-making. In the context of
DCD, one option must include the possibility that although unlikely, their family member may
survive. When it appears that death is inevitable, transparency and ethical practice dictate that the
family need to know that death is probable, that the family member is receiving optimal care, and
their end of life wishes and dignity are respected.

It is important to ask the family about their family members’ donation wishes and to
advocate on their behalf to ensure their hopes and deep hopes are recognised and organ and
tissue donation wishes supported if feasible. It is recommended that this level of care is included
in the end of life care for every dying patient. In summary, early recognition by a family that an
injury is un-survivable allows the staff to explore the families’ expectations about death and
organ donation decisions early, and to have services and processes available to both support
optimal end of life care and decision making.

In this study nurses played a role in providing compassionate and expert end of life care. Nurses were pivotal in providing palliative care techniques to help the families create ceremonies to farewall their family member which is an important practice for end of life care. It is recommended that planning for the separation of the family from the body of the deceased family member should be a standard part of end of life care in the critical care environment.

Therefore, nurses will need to play a more defined role in collaborating with families, doctors and the multidisciplinary team to address the information and advocacy needs of the family. In the context of decision-point three, the role of the nurse in requesting organ donation has been poorly explored in the Australian context. Historically, this has been seen as part of the doctors’ role. A patient centred collaborative approach to end of life care, the use of ‘continuity of care models’ for supporting families throughout this time and resources to ensure their physical and psychosocial needs should be addressed. Kesselring et al. (2007) recommended a person, not organ centred approach to communication with families of brain dead family members and this study also recommends such an approach.

This study showed that sometimes callous behavior and staff communication failures led families already suffering physical and emotional fatigue related to shock and grief, to suffer increasing levels of distrust and fear and in the care provided to their family member and organ
donation processes. This problem can occur in end of life care practices in critical care environments in which organ donation decision making is situated. It is vital that staff maintain a focus on remembering that humanity rests on the valuing of life and personhood of the deceased when providing end of life care. The suffering that many families in this study experienced was unacceptable and preventable.

5.5.7 Implication for practice at decision-point 1, 2 & 3: Emergency departments

When a patient is unlikely to survive, early decisions about whether to continue treatment and try to maintain the patient’s physiological function or continue physiological support to enable organ donation and end of life care are made in the emergency department. Continuing physiological support requires the use of invasive technological support such as ventilation and management of blood pressure, which in the context of the overwhelming injury to the person is only likely to be of benefit in allowing organ donation, and not in saving the persons’ life. This clinical dilemma is encountered regularly in the critical care environment, and particularly in the emergency department where rapid assessment and decisions are made about initiating or continuing life sustaining interventions and support such as intubation and CPR. In this study families were asked to agree to donate their loved ones organs whilst still in the emergency department and this has important implications for practice. However, there is limited guidance or procedural support for emergency physicians or nurses who may be required to approach the question of organ donation and manage the situation (Robey & Marcolini, 2013).

This situation may be further complicated when a patient is admitted to a small emergency department in a regional centre. Limited staff expertise plus resources may
compound the dilemma at a practice and ethical level. In this study scarce critical care services became an issue for some families of patients from regional locations when services were limited to initial stabilisation, but precluded the support required to enable organ donation processes. The limited services in the remote setting meant that organ donation would only be possible if the patient was transferred to a large centre with critical care facilities, or if the organisational processes required for donation and transplantation were set in train early and a specialist team was immediately available to travel to the location and manage the situation.

Emergency physicians and emergency nurses have an important collaborative role to play in the assessment of the patient and the family support needs. It is recommended that emergency physicians and nurses are supported with ongoing educational programs regarding the processes of organ and tissue donation. Such programs will enable them to anticipate and respond to situations where deceased organ and tissue donation is considered. Emergency and intensive care staff require ongoing professional development education to develop skills regarding transparent communication and managing perceptions of conflict of interest when they arise. It is important that families and patients are aware that the goal of the staff is to try to save the life of the dying patient. When communicating this to the family, the staff has an obligation to inform the family when they know there is little chance that their family member will survive. This is also an appropriate time for end of life wishes about organ donation to be considered, and support services offered.

Increasingly in Australia, organ donation is discussed in the hospital setting shortly after dying patients are admitted to emergency departments. Importantly, this allows ethical decision
making before treatment is either instituted or withdrawn. In these situations, it is important to understand how the organ donation request may be perceived, and how it should be approached. Resource pressures require doctors and nurses to limit admissions of critically ill patients to intensive care units. The idea that critical care services are not a patient ‘right’, but are provided by invitation only complicates options for selectively planning the timing of family organ donation discussions. The triaging and rationing of retrieval services for critically ill patients located in remote or regional locations before transfer to specialist metropolitan hospitals further contributes to the contextual complexity of family decision-making. It is necessary to consider the increasing role that emergency department staff play in ensuring that every dying patient and their family have the choice to donate. These decisions could be approached more transparently and frequently in the emergency department which has significant implications for resource saving and may contribute to improved transplantation rates.

5.5.8 Implication for practice at decision-point 3:
Declaring death and organ donation processes

As previously mentioned in Chapter 1, the donation request is complicated due to the difficulties in accurately predicting brain death in ventilated patients with un-survivable brain injuries, and the time of death for patients who have ventilation withdrawn following un-survivable brain injuries. Further, in circumstances where a decision is made to cease treatment prior to death, the donation decision must precede the diagnosis of death. This means that staff and families are required to comprehend the sequence of death and the organ donation process whilst also preparing for the possibility that death may not eventuate in a time frame that enables organ donation. The families in this study had no insight into the complexity of the decisions
they were required to make. This was further compounded as they were not provided with written information or sufficient verbal information to make an informed decision.

Therefore, transparent information and education about the processes required to enable organ donation must be made available to the community and also to families when making organ donation decisions. The information should be available on websites plus other avenues in a written format. Consumers should be included in the creation of these resources to ensure that they are appropriate to different demographic and cultural groups. The information should be made available via hospitals, health care departments and organisations, including the nursing profession and medical professions.

5.5.9 Implications for practice at decision-point 4:

Acknowledgement, reciprocity and bereavement care

Families should be given the opportunity to discuss their experience and to check their understandings with health professionals involved in the care of their family member following the death. The results of this study showed that such an opportunity was not afforded to the nine families who participated in this study. It is important that the donor and their family be acknowledged for their gift of donation regardless of the transplantation result. These actions recognise the possibility that donation may have required the family to sacrifice. This sense of sacrifice can be minimised with care, support and acknowledgement.

Improving practices following a donation decision should include follow-up and support of every decision-maker following their experience by the treating health care professionals who
have established a rapport with the decision-maker. There should also be public and private
acknowledgement for families who agree to organ donation and their family member of the
sacrifice and gift involved. It is also recommended that avenues for communication between
donor families and recipients should be explored and improved. For example, donor families and
recipients should be given the opportunity to meet if mutually agreed upon and following ethical
practices. Recipients and those awaiting transplantation should be provided with education and
support by the health care professionals involved in their transplantation care to assist them in
writing a letter of thanks to the donor family if they so desire.

In summary, the researcher believes that the above mentioned implications and
recommendations need to be addressed. Importantly, the three constructs of deep hope, hope and
trust need to be recognised as major considerations at each stage of the organ donation process.

5.6 Limitations of the study

The intention of the researcher was to explore the experience and perceptions of families
who had agreed or declined deceased organ donation on behalf of a family member. Therefore,
the purpose of this study was to obtain rich, valuable data that would shed some meaningful
insights into the phenomena of organ donation. As a result, the findings of this small study
cannot be generalised; however, they do have significant practical and policy implications at a
micro, meso and macro level. The findings from the study are a representation of the family
views and therefore the interpretation of this study has sought to provide an insight into what it is
like to be a family member making this decision. The study was not designed nor was it within
the scope of the study to explore the complex ethical and political paradigm that surrounds the decision making experience.

A limitation of the study was its small sample size and so a recommendation for further research is to conduct a larger qualitative study on the topic. The conclusions regarding women and in particular mothers however, must also be recognised in the context of the disproportionately high representation of females, and mothers in particular who respond to organ donation studies, and who the literature identifies are more inclined to offer donation of their young children’s organs to bring meaning from the death (MORI, 1996).

5.7 Recommendations for further research

The first recommendation is to test the 4 point decision-making process that has been embedded within the modified theoretical framework and which is discussed in the following section. I recommend that research should be conducted with organ and tissue donation decision-makers to examine the influence of information and communication at each of these decision points and also across the decision experience. It is recommended that this proposed study be conducted in both retrospective and prospective contexts of decision-making experiences.

Second, this study has shown that there is a gap in the literature regarding the specific role of the mother in organ donation decision-making. There has been little research specifically into why females are more highly represented on organ donor registers. It is a phenomenon which is well recognised but poorly understood. Furthermore, the fact that females, specifically mothers were the instigators of offers of donation is a significant finding and requires further
study. This study has identified that mothers or female family representatives are influential in decision-making at this critical time. It is therefore important to explore the specific needs and expectations of this group in an effort to understand this phenomenon and to better understand their expectations. It is possible that this is a culturally specific phenomenon and is confined to populations in Australia suggesting that it is important to conduct further research across a diverse population. Furthermore, it is important to undertake research to examine the role of the mother/female in families’ interpretations of hope, deep hope and trust in decision-making contexts.

Third, the model utilised in this study has identified that hope, deep hope and trust are influential in consent and decline decisions. It is important to explore the validity of this model in further research. It would be helpful to conduct a large study of donor and non-donor families to specifically explore the role of hope, deep hope and trust in identifying the needs and expectations of decision-makers. This model may be applicable in other contexts of health care decision-making and therefore could be utilised in research with families who make decisions in complex circumstances such as end of life care, complex therapies and other emotionally challenging or difficult or life altering decisions.

The fourth recommendation from this study is for research to be conducted in Australia into the effect of using designated requestors of organ donation to remove any perceptions of conflict of interest from the request for organ donation by having a team request organ donation separate to the treating health care professionals. This research could be conducted as a prospective large mixed method interventional multi-centre trial. Such a study could compare the
outcomes of hospital performance in organ donation and prior to an intervention which involves a decoupling process using a specialised team. This would comprise education and training of health professionals who would be given specific education and skills to understand and facilitate the entire organ donation process for transplantation. They would be surveyed before and after the intervention regarding their attitudes and knowledge of organ donation, and the donation performance at the sites of the interventions would be measured to assess the effectiveness of the intervention.

The fifth recommendation for further research is a proposed study to examine the effect of decoupling the idea of ‘un-survivability’ and not ‘brain death’ as a trigger point in discussions between staff and families about organ donation should be conducted in Australia. Previous studies (Gortmaker et al, 1998) have shown the positive effects on organ donation consent when the concept of decoupling the request for organ donation from the declaration of brain death is employed. The findings from this study identified that once families understand that death is inevitable, they then find it more acceptable to consider questions regarding organ donation. This understanding may occur before a declaration of brain death or following a declaration of brain death. Therefore, the proposed research could examine the influence of decoupling families’ ideas of their loved ones survival with discussions regarding organ donation.

Finally, it is recommended that future research is conducted into the role of the nurse in requesting organ donation and in improving collaborations across the multidisciplinary team to efficiently and compassionately optimise patient and family centred care.
5.8 Conclusion

In conclusion, this study has contributed to the literature in three significant ways. First, it has identified that the family deceased organ donation decision-making process is complex and consists of 4 distinct points. This study found that these points, pivotal for the acceptance of deceased organ donation, have not been identified in previous studies. It is simplistic and paternalistic to assume that the family decision to donate can be entirely influenced by a previously stated intention to donate at decision point one by a dying or deceased loved one, or that this policy in isolation will increase deceased organ donation consent decisions and transplantation rates.

The second major contribution is the significant finding that mothers are a major influencer in the family decision-making process which has important implications for policy and practice. The role of information and compassionate communication to address the expectations of the mother, her family and the health care team cannot be understated. Third, the modified model of decision-making utilising hope, deep hope and trust has the potential to guide and explain difficult and complex family decisions in the context of health and well-being and can play a significant role in helping to identify situations which can lead to distrust, complicated bereavement and human suffering.

This study has provided important insights into the factors that influence family decisions to agree or to decline deceased organ donation; as well as revealing the effect that the decision-making process has upon families and their ongoing well-being. The results of the study showed that when trust flourished, decision-making based on the hopes and deep hopes of family
members and the deceased led to decisions that supported the altruistic ideal of deceased organ
donation to benefit others. In this study there is clear evidence that health professionals
practicing in an open and transparent way with the patients’ family as partners can empower the
affirmation and development of deep hope, hope and trust for the families they care for facing
the task of end-of-life decision-making. Aligning hope for a peaceful death with end of life organ
and tissue donation for transplantation practices could maximize donation consent rates and
ameliorate suffering. This goal can be achieved within existing resource structures. However, it
requires attention to improving the quality of care provided at end of life, and transparency in
drawing from expertise in palliative and paediatric care areas to restore humanity to critical care
end of life care practices and organ donation.

Organ donation decision-making must be integrated as a standard part of quality end of
life care which includes providing the dying and their families with the right to a peaceful death
with their physical, psychosocial, spiritual and cultural needs being met in a dignified and
respectful way. Doctors and nurses are professionally responsible to recognise the vulnerability
of the dying and their family members, and to advocate and collaborate to provide patient and
family centred care that meets human rights standards. Organ donation decision-making and
processes are part of this care. Law and policy makers, ethicists and professionals associations,
health care organisations, health communicators, doctors and nurses must be held accountable
for their practice in this area using transparent internal and external quality review processes
which ‘hear’ the voices of those who are most affected in the community and address power
imbalance. By addressing the deep hope to create meaning from death, and allowing hope to
flourish, it is may be possible to meet the needs of not only those in need of transplant and their
families, but the needs of donors and their families. The idea of the right to a peaceful death and organ donation should be enshrined in practice.
doi:10.1136/bmj.b3911.


Australian Organ and Tissue Donation and Transplantation Authority (2012). National Reform
Agenda, Strategic Priorities. Retrieved from

Australasian Transplant Coordinator Association (2008). National Guidelines for organ and

Schlemmer, B. (2000). Half the families of intensive care unit patients experience
inadequate communication with physicians. Critical Care Medicine, 28 (8), 3044-9.

Banner, N., Thomas, H., Curnow, E., Hussey, J., Rogers, C. & Bonser, R. Steering group of the


Bishop, R. (2005). Freeing ourselves from neo-colonial domination in research: A Kaupapa


Bramstedt, K. (2013). Family refusals of registered consents: the disruption of organ


Dierckx de Casterle, B., Verhaeghe, S., Kars, M., Coolbrandt, A., Stephens, M., Stubbe, M.,


DeVita, M., Snyder, J. & Grenvik, A. (1993). History of organ donation by patients with cardiac
death. *Kennedy Institute of Ethics*, 3(2), 113-129.


Hansen, J. (2013, November 2, 10pm). Gift of life campaign: Patient's are missing out on life


rapid response team in nosocomial end-of-life care. *Critical Care*, 17, 224.
doi:10.1186/cc11856

negative beliefs about organ donation upon death. *Psychology, Health and Medicine*,

Donation and Transplantation Activity*. Organs, Tissues &Cells, 15, 147-151. Retrieved
from http://www.europeantransplantcoordinators.org/clinical-resources/irodat/

(2012). Factors that influence the decision to be an organ donor: a systematic review of
the qualitative literature. *Nephrol Dial Transplant*, 27, 2526-2533.

Jacoby, L. & Jaccard, J. (2010). Perceived support among families deciding about organ
donation for their loved ones: donor vs nondonor next of kin. *American Journal of


politics and inquiry. In Denzin, N. & Lincoln, Y. (Eds.). *The Sage Handbook of
Qualitative Research*. (3rd ed.) (pp.887-908). Thousand Oaks, CA. USA.


ISSN: 00411345.


Organ_Donation_Lawrence_paper.pdf


In B. Tait (Ed.). *More than a footnote. The story of organ transplantation in Australia and New Zealand* (pp. 3-21). North Melbourne, Victoria: Academic Scholarly Publishing Pty Ltd.


Morrison, J. (2014). The Australian transplant system is facing a state of emergency. Let’s give


National Health and Medical Research Council. (2007). Joint NHMRC/AVCC statement and guidelines on research practice, NHMRC.


Robb, N. & Greenhalgh, T. (2006). “You have to cover up the words of the doctor” The


Savaria, D., Rovelli, M. & Schweizer, R. (1990). Donor family surveys provide useful


Steinberg, A. (2012, personal communication, October, 22.).


Watson, C., Dark, J. (2012). Organ transplantation: historical perspective and current


World Health Organisation (2010). Guiding principles on human cell, tissue and organ
transplantation. Statute Number WHA63.22. Retrieved from

http://www.who.int/transplantation/Guiding_PrinciplesTransplantation_WHA63.22en.pdf


APPENDIX 1

Invitation to Public to Participate in the Study

This is an example of the narrative that was used for recruitment across a range of communication media.
The factors that influence families’ organ donation decisions.

A doctoral research candidate in Health at the University of Canberra is conducting research into the experience of bereaved families who have made the decision to decline organ donation. This research hopes to shed light on some of the factors that influence bereaved families when making a donation decision. There has been limited research in Australia on this topic to guide health care workers in caring for families required to make these decisions.

National statistics indicate 40 to 50% of Australian families faced with the death of their relative and a request to donate, will decline donation of their relatives’ organs. In other countries with a similar demographic to Australia, the number of families that agree to donation is higher.

The candidate is seeking media awareness opportunities to bring to this research project to the attention of families who have been asked to donate their deceased loved ones organs in the last three years. We wish to provide families who want to participate in this research the opportunity to contribute. They will be asked to participate in a strictly confidential recorded interview to describe their experience with the researcher at a negotiated time and place.

The aim of the research is to understand the factors influencing bereaved families making a decision to decline organ donation. This research is expected to lead to improvements in the care given to bereaved families in hospitals, and will potentially lead to more families agreeing to organ donation and the benefits that arise from that outcome. This research proposal has received ethics approval. Free counseling is available through LifeLine Australia 24 hours a day on 13 11 14, or beyondblue on 1300 22 4636.

For more information or feedback and comment, please contact: Media contact:

Amanda Powell: T: +61 (0)2 6201 5422; M: +61 (0)408 826 362; F: +61 (0)2 6201 5347
E: amanda.powell@canberra.edu.au Or

Researcher: Holly Northam: T: 02 6201 2135, E: holly.northam@canberra.edu.au

If you would like to talk to an independent person about this research please contact

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APPENDIX 2
Committee for Ethics in Human Research Approval
8th July 2011

Ms Holly Northam  
Faculty of Health  
University of Canberra  
BRUCE ACT 2617

Dear Holly,

The Committee for Ethics in Human Research has considered your application to conduct research with human subjects for the project entitled *The factors that influence families who decline organ donation.*

Approval is granted until 01/01/14 the anticipated completion date stated in the application.

The following general conditions apply to your approval.

Those requirements are determined by University policy and the *National Statement on Ethical Conduct in Research Involving Humans* (National Health and Medical Research Council, 2007).

| Monitoring: | You, in conjunction with your supervisor, must assist the Committee to monitor the conduct of approved research by completing and promptly returning project review forms, which will be sent to you at the end of your project and, in the case of extended research, at least annually during the approval period. |
| Discontinuation of research: | You, in conjunction with your supervisor, must inform the Committee, giving reasons, if the research is not conducted or is discontinued before the expected date of completion. |
| Extension of approval: | If your project will not be complete by the expiry date stated above, you must apply in writing for extension of approval. Application should be made before current approval expires; should specify a new completion date; should include reasons for your request. |
| Retention and storage of data: | University policy states that all research data must be stored securely, on University premises, for a minimum of five years. You and your supervisor must ensure that all records are transferred to the University when the project is complete. |
| Changes in contact details: | You should advise the Committee of any change of address during or soon after the approval period including, if appropriate, email address(es). |

Please add the Contact Complaints form (attached) for distribution with your project.

Yours sincerely  
Committee for Ethics in Human Research

---

**Michaela Dalgleish**  
Ethics & Compliance Officer  
Research Services Office  
T (02) 6201 5870 F (02) 6201 5466  
E Michaela.Dalgleish@canberra.edu.au  

www.canberra.edu.au  
Postal Address:  
University of Canberra ACT 2601 Australia  
Location:  
University Drive Bruce ACT  
Australian Government Higher Education Registered  
Provider Number (CRICOS): 00212K
18th February, 2012

Professor Frances Shannon, Chair
Committee for Ethics in Human Research
University of Canberra
Bruce, ACT, 2617

Dear Professor Shannon,

Re: Request for a second sample of participants for PhD study – Ethical clearance initially received on 8th July 2011. Number: CEHR 11-60

I would like to request approval to recruit a second sample of participants for my PhD research study titled ‘The factors that influence families who decline organ donation.’

Following review of the initial data collection, it has become clear to my Supervisors, Professor Mary Cruickshank and Assistant Professor Gylo Hercelineskiy and myself that it would be beneficial to expand the range of participants in this study to include those who have agreed to organ donation as well as those who have declined.

The initial data collection has provided evidence suggesting that within the hospital environment there are a number of events and experiences that occur both for non-donor families and donor families that may contribute to non-consent/consent decisions. It is therefore proposed that by sampling donor family participants with an opportunity to recount their case experiences as well there will be a more diverse representation of the experience, which has the potential to provide rich, insightful analytic data. It is anticipated that approximately 15 donor participants will be recruited through the recruitment strategies that were approved by the University of Canberra Committee for Ethics in Human Research in 2011.

Yours sincerely,

[Signature]

Holly Northam
PhD Candidate, u846772

Holly Northam, PhD Candidate, u846772, Ethics Application: CEHR 11-60
Hi Holly,

Your variation request is now approved.

Kind Regards,

Chanel Slater  
Ethics & Compliance Officer  
Committee for Ethics in Human Research (CEHR)

T: +61 (0)2 6201 5870  
F: +61 (0)2 6201 5999  
E: chanel.slater@canberra.edu.au

Research Services Office (Room: 1 D 88)  
At: Building 1, Kirinari Street, Bruce, ACT 2617  
W: http://www.canberra.edu.au/scresearch

Australian Government Higher Education (CRICOS)  
Registered Provider number: #00212K

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APPENDIX 3

Letter of invitation to the study
Dear xxxx,

Thank you very much for your generous offer to contribute the research project, *The factors that influence families deceased organ donation decisions.*

We have found that you meet the inclusion criteria for this research project and we would be very grateful if you could please read the enclosed information sheet and consent form which describe the requirements for being a part of this research. It is important that you have an opportunity to think about what will be involved in taking part in this research so as to ensure that you are very certain that it is something that you would like to do. I have provided detail about what you can expect in being a part of this research. The most important thing however, is that you feel comfortable and willing to tell your story, that your privacy will be protected, and that you are aware that you can change your mind at any time without any consequence.

Once you have had an opportunity to read and consider the material that I have sent to you, please feel free to contact me to let me know if you wish to participate. If I have not heard from you I will contact you one week after sending the information to discuss if you have any questions and if you would like to continue or not. If you are still comfortable about participating, I will arrange with you a date, a time and a place that suits you where we can meet for the confidential recorded interview. If you no longer wish to be involved in the research please let me know as soon as possible as I will ensure that any data that relates to you is destroyed.

Some people may find it difficult and distressing to think about their experience, and to talk about their grief. We would like to take the opportunity to ensure that if you would like to talk to a professional counselor about any difficulties that may be worrying you a free counseling service is available through
LifeLine Australia and can be contacted 24 hours a day on 13 11 14, or beyondblue on 1300 22 4636. Your local health service provider will also be able to help you.

Thank you very, very much for your interest and assistance in this research.

Yours sincerely,

Holly

Holly Northam PhD Candidate

Email: holly.northam@canberra.edu.au

Ph: 0412 289 295.  University of Canberra, Faculty of Health, Disciplines of Nursing and Midwifery.
APPENDIX 4

Participant Information
My name is Holly Northam, and I am doing a research PhD in Health at the University of Canberra.

**Project**

This research seeks to identify how families in Australia make the decision to agree or decline organ donation. This purpose of this research is to explore decision-making processes for families who decline organ donation. Specifically it aims to explore avenues to maximise Australian consent rates.

**Benefits of the Project**

Information gained from the research will help improve the experiences of bereaved families who are asked to make an organ donation decision. It is expected that this will lead to an increase in the number of families agreeing to organ donation. This outcome will have benefit to patients in need of transplantation and the Australian community.

**Participant Involvement**

The families who will be able to contribute to the research are those who have been asked to donate their deceased relative’s organs in the last three years. Families who take part in the research will be asked to participate in a confidential recorded interview to describe their experience at a negotiated time and place. It is very important that families should not participate if they believe that it will cause additional distress to them or to their family. If you believe your family would like to contribute to this research, or you know a family who may be interested and they wish to contact me, please
1) Contact the researcher (Holly) by ringing 02 6201 2135 and leaving a message, or by emailing holly.northam@canberra.edu.au

2) I will return your call within 48 hours and ask you to give your permission to complete a short confidential telephone survey. This survey will ask you to provide information which will help us to make sure that you and your families experience fits into the requirements for the research project

3) You will be contacted within a week by the researcher to let you know if you and your family will be included in the research project and a letter will be sent to you and your family. It will either formally thank you for your interest and let you know that your kind offer will not be required,

Or

4) It will include a letter of invitation to participate in the research along with the Participant Information Sheet and a Consent Form which you and your family will be asked to sign by the researcher before the interview takes place.

5) If you and your family agree to participate in the project the researcher will contact you and make arrangements to meet personally with you and your family for the recorded interview. The researcher will want to make sure that everything is done to make sure that you and your family are supported in having the interview.

6) At the time of the interview the researcher will come to the pre-arranged interview place and introduce herself to you and to your family. She will explain the research project and make sure that everyone knows that the recorded interview may be stopped at any time without consequence. She will make sure that everyone has signed the Family Participant Consent Form and that everyone has a copy of the Family Participant Information Sheet with the numbers that can be used for support.

7) At the end of the interview the researcher will let the participants know that she will be in contact to thank them. She will offer to send a copy of the transcript and voice file of the interview to allow participants the opportunity of checking the content is accurate. If participants indicate a desire to have a copy of the findings they will be sent to the participants upon completion of the study before publication.

Participation in the research is completely voluntary and you and your family may, without any penalty, decline to take part or withdraw at any time without providing an explanation, or refuse
to answer a question. There are no benefits or rewards for the families who participate other than the sincere thanks of the researcher.

**Confidentiality and Data Storage**

Great care will be taken to ensure that any reports of the data do not identify any individual or their circumstances. Your information is strictly confidential and nobody will be able to tell that you took part in this study from any of the reports, discussions or conferences where the findings are discussed. Please be assured that all the information collected will be de-identified stored securely in a locked cupboard, and on a password protected computer file which can only be accessed by the research team throughout the project. It will be stored at the University of Canberra for seven years according to university protocols.

**Ethics Committee Clearance**

The project has been approved by the Committee for Ethics in Human Research of the University of Canberra.

**Questions and Concerns**

Some families may find it difficult and distressing to think about their experience, and to talk about their grief. If you would like to talk to a professional counsellor about any difficulties that may be worrying you and your family, a free counselling service is available through LifeLine Australia and can be contacted 24 hours a day on 13 11 14, or beyondblue on 1300 22 4636. Your local health service provider will also be able to help you.

If you would like to talk to an independent person about this research please contact
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APPENDIX 5

Plain Language Statement
Instructions:

Thank you very much for contributing to this research project. All the Family members who wish to participate in this research need to sign the Consent Statement to being part of the research. The researcher will explain about what will happen in the research interview with all the family and answer any questions that you have before the **recorded confidential interview** starts and at any time through it and afterwards. Before you sign this consent form please make sure you have read the Participant Information Sheet and made sure that you are comfortable with what it says.

**Consent Statement**

I have read and understood the information about the research. I am not aware of any condition that would prevent my participation, and I agree to participate in this project. I have had the opportunity to ask questions about my participation in the research. All questions I have asked have been answered to my satisfaction.

Please indicate whether you agree to participate in each of the following parts of the research (please indicate which parts you agree to by putting a cross in the relevant box):

- [ ] I have read and understood the Participant Information Sheet and kept a copy.
- [ ] The risks of being part of this research and inconveniences have been explained to me
- [ ] I know what I am expected to do and what this involves
- [ ] All my questions have been answered to my satisfaction
- [ ] I am aware that I will not directly benefit from this research
- [ ] I can withdraw at any time from the research without consequence
- [ ] I understand that my personal information will be kept private
- [ ] I am satisfied to participate in the research as it has been explained to me and my consent is freely given
- [ ] I can obtain a copy of the final report when it is complete
- [ ] I agree to the publication of the results of this research provided that any details that might identify me are removed.
Name.................................................................................................................

Signature...........................................................................................................

Date ..............................................

A summary of the research report can be forwarded to you when published. If you would like to receive a copy of the report, please include your mailing (or email) address below.

Name.................................................................................................................

Address..............................................................................................................