THE LIVED EXPERIENCE OF ORGAN TRANSPLANTATION: MIRACLE OR MEDICINE?

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Declaration

I declare that this thesis is my own account of my research and contains as its main content work that has not previously been submitted for a degree at any tertiary education institution.

Geraldine O’Brien
Abstract

Transplantation has revolutionised the management of end stage organ disease, and is currently the treatment of choice in many developed western nations. The success of this treatment has led to an increasing demand for it, and concomitant increase in the demand for transplantable organs. Organ scarcity is widely acknowledged as the dominant, and most persistent, problem faced in contemporary transplantation. Scarcity of available organs undergirds the gift-of-life metaphor, upon which all transplantation discourses have been founded (Fox & Swazey, 2002). Gift-of-life discourse is routinely utilised in a bid to increase donation rates and enforce a ‘construction of care’ in recognition of, and reciprocity for, the scarce and precious gift received (Sothern & Dickinson, 2011).

Shaw (2012) argued that gift-of-life rhetoric is prescriptive; directing, in large part, what can be felt and said in the context of transplantation. This can be problematic, as although transplantation undoubtedly extends life, it does not do so without incurring physiological and psychological cost. The immunosuppression regimens that recipients must adhere to and the psychosocial outcomes of transplantation mean that, in effect, transplantation may represent the exchange of one set of hardships for another (Sharp, 2006). Recipients often exist in a state of ‘persistent liminality’, caught between the worlds of the healthy and the sick (Crowley-Matoka, 2005).

This research was undertaken to explore the lived experience of transplantation. I was particularly interested in exploring how gift-of-life understandings of transplantation might influence this experience. Given the normative expectation of gratitude in response to a gift/benefit received (McCullough & Tsang, 2004) and the centrality of gratitude to gift-of-life discourse (Shaw, 2012), I was also interested in exploring gratitude in the
context of transplantation. Participants were 19 (i.e., 13 heart, 6 liver) recipients, and 11 (i.e., 1 liver, 10 kidney) prospective recipients. I conducted semi-structured interviews, and adopted an interpretative phenomenological approach to analysis.

Results indicated that a generic model cannot be applied across the range of transplantation experiences. The psychosocial experience of receiving a heart is not the same as the experience of receiving a liver, or that of receiving a kidney. Social constructions of the particular organ being received (e.g., the liver, a life-saving organ, is more ‘precious’ than the kidney, a quality-of-life organ), and of those most likely to need that organ (e.g., liver recipients are alcoholics who are responsible for their illness) shape the experience of receiving (or waiting to receive) a heart, liver, or kidney. While all participants acknowledged an awareness of gift-of-life discourse, and its potential to direct their experience (e.g., considerations of whether or not they were worthy or deserving of the gift-of-life), many reported they did not understand transplantation in this way. Recipients did not uniformly express gratitude and, here too, the particular organ being received appeared to exert an influence (e.g., heart recipients most often expressed gratitude, while many liver recipients did not report gratitude in relation to their transplant). These findings provide new insights with respect to the experience of transplantation, and also to the experience of gratitude.
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CHAPTER ONE

Introduction

The body is both a biological and social object, perhaps never as blatantly so as it is in transplantation. Once a body is split into parts and transferred to one or more other bodies, the organs become both a biological and social bond between donor and recipient. The vulnerability of the human body that is exposed through this dependence on other bodies and their parts is a fascinating social fact worthy of examination (Mauldin, 2008, p. 630).

1.0 Introduction

The realm of transplantation is one in which both the social and the biological nature of the human body is pertinent, if not always highly visible. Transplantation is a medical event in that bodies (as biological entities) are healed or repaired, depending on the perspective taken, and life is extended. It is a value-laden social phenomenon to the extent it represents a deeply significant exchange between ‘bodies’. It is also social to the extent that particular bodies are judged worthy of healing/repair while others are not, and life is extended for some while for others it is not. Furthermore, it is social in that bodies cannot be extracted from their situatedness in the world in order to be healed or repaired. The idea of an autonomous body separate, and separable, from the environment is a myth (Einstein & Shildrick, 2009). The ‘body’ (person) exists in the context of the social environment, and in reciprocity with it. Einstein and Shildrick (2009) argued that the contingencies of ‘lived lives’ must be taken into consideration when attempting to better
understand health and illness, and the influence that biotechnologies (like transplantation) have on individuals. Failure to do so can detract from the effectiveness of medical intervention and care.

Advances in transplant medicine have made it possible to preserve and extend the life of individuals with end-stage organ disease. As emphasised by Frank (1995), medicine’s triumph can be seen in the increasing number of those living, who would have otherwise died. Although ‘the saved’ move from the Kingdom of The Sick back to the world of the healthy (i.e., the Kingdom of The Well), they no longer enjoy full citizenship. They instead have only “permanent visa status, that visa requiring periodic renewal. . . . [They are, thereafter,] always subject to expulsion” (Frank, 1995, p. 9). Anxieties elicited by the fear of organ rejection (post-transplant), as well as the daily toil of dealing with immunosuppressant medications and their inevitable side effects, take their toll. Sharp (1995, 2001), and others (e.g., Crowley-Matoka, 2005; Kierans, 2005, 2011; Shaw, 2012; Shaw, Bell, & Webb, 2012; Sothern & Dickinson, 2011), have noted that the biomedical view of organ transplantation as a bounded event, which ends once a heart, liver or kidney is successfully replaced, belies the complex, dynamic and generative process that more accurately represents the experience of receiving an organ. Organ recipients do not just ‘pick up the pieces’ of their life as it was pre-illness. Instead, transplantation profoundly transforms their life and, importantly, their sense of self and place in the world.
1.1 Gift-of-life

The experience of transplantation occurs in a context that is largely shaped by gift-of-life discourse. Sharp (1995) contends that transplant ideology determines the social value of the body, and morally appropriate ways in which to understand the use of its parts. From within this framework, “body parts must not be viewed as commodities . . . [but as] precious gifts given willingly to others in need” (p. 361). Gift-of-life discourse has become the sanctioned discourse of transplantation (Svenaeus, 2010), and a powerful determinant of the transplant experience (Fox & Swazey, 2002). It is neither morally nor politically neutral, though, and the way in which recipients should think, feel and respond to the receipt of an organ transplant (i.e., the gift of life itself) is structured through this societally endorsed framework (Shaw, 2012; Shaw et al., 2012).

A social contract is forged in the giving and receiving of an organ (i.e., gift) for transplant. Gift exchange theory (GET; Mauss, 1970) has been considered an appropriate framework within which to explore transplantation (Fox & Swazey, 2002; Siminoff & Chillag, 1999; Sque & Payne, 1994). Three obligations are entailed in the social contract of the gift: the obligation to give, the obligation to receive, and the obligation to reciprocate. Meeting the obligation to reciprocate can be particularly challenging for transplant recipients. In the case of cadaveric donation, the donor is no longer living, but significant pressure is still borne by the recipient to meet the terms of the social contract. As highlighted by Sothern and Dickinson (2011), transplant recipients cannot be passive in receiving the gift-of-life but must instead adhere to a ‘construction of care’, that is understood as a demonstration of both worthiness and reciprocity for their gift-of-life.
1.2 Gratitude, and the ‘tyranny of the gift’

The concepts of gift exchange and gratitude make comfortable bedfellows. The moral imperative of gratitude indicates that it is experienced in response to the receipt of a benefit/gift (perceived as being of value), which has been given at some cost or effort on the part of the benefactor (McCullough, Kilpatrick, Emmons, & Larson, 2001). It is feasible to suggest, then, that considerable gratitude might be experienced in relation to the gift of life. It has been argued that a compelling obligation to reciprocate is taken on by those who receive an organ transplant, and gratitude, as a form of reciprocation, is central to gift discourse in the context of transplantation (Shaw, 2012; Shaw et al., 2012; Sothern & Dickinson, 2011). However, reciprocation can pose a dilemma in the circumstance of transplantation. To whom should one feel grateful? To whom should gratitude be expressed? Is it possible to be grateful enough to sufficiently reciprocate for the gift-of-life? This quandary gives rise to the ‘tyranny of the gift’: the psychological and moral struggle experienced by some recipients in their attempt to reciprocate appropriately in the context of perceived magnitude of the gift received (Fox & Swazey, 2002).

1.3 Organ scarcity

Organ scarcity has been described as the most persistent problem in transplantation, and one that underpins (either implicitly or explicitly) many of the current ethical concerns in this context (Jonsen, 2012). ‘Scarcity anxiety’ permeates the entire realm of transplantation (Sharp, 2006). It impacts potential recipients as they are evaluated for transplant waitlists, and then await the availability of an organ knowing that all who are evaluated are not waitlisted. Once waitlisted they again face uncertainty, as there is no
guarantee an organ will be found in time. Scarcity anxiety extends to potential donors and families of cadaveric donors (e.g., they may feel obligated or pressured to donate, given the shortage of available organs and the impending death of potential recipients). It also affects healthcare professionals, who act as ‘gatekeepers’ of the scarce and precious resource: deciding who is, and is not, selected for transplantation and placed on a waitlist; and who is allocated an organ when one becomes available (Fox & Swazey, 2002). Knowledge of the extent of organ scarcity, and the scarcity anxiety elicited by this knowledge, serves to further emphasise the magnitude of ‘the gift’ for those who are in receipt of it. Awareness of how fortunate they are in relation to those others who have not received (and may not ever receive) a transplant might arguably exacerbate the risk of experiencing the ‘tyranny of the gift’.

1.4 The current study

There is always more at stake (in research and health care) than the restoration and repair of a decontextualised body or any one of its parts. . . . [there] is the need to design empirical work that variously takes into account the effects of one corporeal system on another: how intervention into and alteration of one part of the body modifies the entire organism, and ultimately, how the world writes on the body (Einstein & Shildrick, 2009, p. 298).

I undertook this research to explore the organ transplantation experience: to better understand how transplantation (i.e., the replacement of a body part) affects the “entire organism” that is the organ transplant recipient, and how “the world writes on” those who have experienced this potentially life-extending, life-altering procedure. Within the
broader framework of the study, I focused on the experience of gratitude, with the aim of advancing knowledge and understanding of gratitude and how it relates to gift-of-life discourse.

The ‘tyranny of the gift’, the psychological/moral sequelae of organ transplantation, might well represent ‘a perfect storm’ for the exploration of the affective quality of the transplantation experience. Feelings of obligation and gratitude do not necessarily fit easily together. If a person feels compelled to meet the terms of the social contract (i.e., feels that he/she is obligated to, or must, reciprocate), he/she might arguably feel indebted rather than grateful. Indebtedness and gratitude, both of which relate to obligation, are distinct responses to the receipt of a gift/benefit (Tsang, 2006). While gratitude has a positive valence and is associated with prosocial action tendencies, indebtedness, with its more negative valence, is linked with avoidance tendencies and/or rejection (Watkins, Scheer, Ovnicek, & Kolts, 2006).

Celebratory discourse may be problematic in the wake of transplantation surgery. As highlighted previously, the depth and breadth of concern with organ scarcity serves to accentuate the magnitude of ‘the gift’ received in transplantation. Despite the awareness of how fortunate he/she might be, the transplant recipient still has to live with the often-significant effects that transplantation has on his/her life (e.g., the numerous side-effects of immunosuppressant regimens, ongoing medical problems, concerns about body image, relationship issues, inability to find employment; financial difficulties).

In relation to my particular interest in gratitude, I was open to the possibility of both positive and negative aspects of gratitude emerging in a context where gratitude is expected, but also where the transplant recipient (existing in ‘persistent liminality’;
Crowley-Matoka, 2005) might not always feel that he/she has a great deal to celebrate. Understanding gratitude in this context, in all its complexity, has the potential to lead to a richer understanding of the affective/psychosocial aspects of transplantation.

1.4.1 Method

In a bid to explore the experience of transplantation and gratitude, as well as other affective responses to transplantation, I conducted an in-depth study of people living in Perth, Western Australia, who had suffered from heart, liver or kidney disease, and had either received or were on the waitlist to receive a donated organ. In exploring this, I adopted an interpretive phenomenological approach. Interpretative phenomenological analysis (IPA) is a qualitative method that has particular utility in the exploration of lived experience, notably so in the context of health and illness (Biggerstaff & Thompson, 2008; Chamberlain & Murray, 2008; Smith, 2004). It is an idiographic approach that centres on the individual’s story, with explicit acknowledgement of the active role of the analyst in accessing the participant’s inner world (Pringle, Drummond, McLafferty, & Hendry, 2011). To this end, the analyst engages in a double hermeneutic; that is, he/she attempts to interpret how a participant is interpreting (i.e., making sense of) a particular experience.

Utilising a semi-structured interview method inevitably results in elicited participants’ narratives being co-constructed with the interviewer (i.e., in the sense that the topics investigated by the interviewer are focused through a particular intellectual/analytic lens). The story told by the participant could, and in all likelihood would, be different if told to a different researcher with a different exploratory focus. Further, the outcome of analysis, based on an interpretive phenomenology approach, is a
collaborative narrative, in that it represents the meanings made by both the participants and the researcher, of the experience being explored (Eatough & Smith, 2008).

### 1.4.2 Expectations and discoveries

At the outset of the study I had anticipated that all organ recipients and prospective recipients would experience gratitude in relation to their transplant and/or treatment. I believed they would be a homogenous group, commonly experiencing gratitude in the context of receiving an organ, or waiting to receive one. I had not considered that I might find differences within the sample such as those that emerged between different organ transplant groups. Or that the participants in what I came to regard as the heart, liver, and kidney groups would talk about such strikingly different psychosocial issues. I had not anticipated that some recipients would report they did not understand their transplanted organ as being the gift-of-life at all, that they did not experience gratitude in relation to their transplant, or that affective responses other than gratitude, such as shame or hope, would emerge as forming an equal (or sometimes even greater) basis of some participants’ stories.

### 1.4.3 Stories

The cure or treatment of disease lies at the heart of the prevailing medical discourse (Frank, 1995). Given the question I posed at the beginning of each interview (i.e., Can you tell me something about the circumstances that led to you being placed on the transplant waitlist?), I learned a considerable amount about the symptoms of, and treatment for, organ failure: the signs of deteriorating organ function; medical appointments, diagnoses and medications; various ventricular assist devices (for those
with heart disease) and dialysis (for those with kidney disease); and ultimately the vast array of tests that formed evaluations for waitlisting. Frank reported his understanding that in seeking medical care, the ill become complicit in a form of *narrative surrender*, whereby they give their story over to the physician: “personal feelings are contextualised within a secondhand medical report” (p. 6). I certainly heard these medical accounts of transplantation.

Medical treatment, though, is only part of the individual’s personal transplant story. As a researcher, I had the privilege of being taken deeper into the lives of organ recipients and prospective recipients, of moving away from these purely medicalised stories. I heard stories of joy: being able to breathe again without strain; being loved, cared for and supported by family and friends; being *alive*. I heard stories of delight: seeing children graduate from university; spending time with grandchildren; going on a much-anticipated holiday; or simply watching a beautiful sunset. I also heard about the significant trials of living with a donated organ: the confusion, vulnerability, sadness, shame and/or anger that, for some, form a large part of the transplant experience. I heard stories of despair and anguish, of being unable to work or find employment, of unfulfilled goals and lost dreams. I was, and continue to be, humbled by the extent to which participants entrusted me with their stories: their willingness to share deeply personal and private thoughts and feelings in the hope that others, who experience transplantation in the future, might benefit. My hope is that this research serves them well, that I have managed to do justice to their stories and the level of trust placed in me.
CHAPTER TWO

Organ Transplantation

In medical arenas, the patient’s story has the potential to be a powerful conduit of meaning, unravelling the complex relationships that lie between the high technologies of medical interventions and the subtle ordinariness of the day-to-day (Kierans, 2005, p. 343).

2.0 Introduction

Organ transplantation involves the removal of an organ from the body of one person (the donor) and placement into the body of another (the recipient). The procedure itself is ‘technical genius’ and thus represents a pinnacle of modern medical accomplishment (Sharp, 2006). However, transplantation is also a highly complex social phenomenon that elicits considerable controversy ranging across a number of domains, including the scientific, medical, political and cultural. It simultaneously crosses a number of boundaries: “between the bodies of selves and others; between the immune system and the environment; between humans and machines; between giving and receiving; between buying and selling; between countries, cultures and communities; and between the rich and poor” (Kierans, 2011, p. 1469). Therein lies the reason for much of the contention that surrounds the development and application of this treatment for end-stage organ disease.

Sophisticated biotechnologies, like transplantation, hybridise bodies and, in so doing, generate new understandings of bodily integrity, the self, and the self in relation to
others. The use of polarising dichotomies (as outlined above) can be reductive. The understandings of transplantation that are generated by them are one-dimensional in nature; they fail to encapsulate the broad range of transplantation experiences across a number of different contexts, and, therefore, do not necessarily explicate, or transpose well to, the lived experience of transplantation (Kierans, 2011).

Organ transplantation can be an ‘uncomfortable’ site for analysis and discussion as it raises the spectre of mortality. Although death is a powerful motivator of human behaviour, its importance in this capacity goes largely unacknowledged (Willmott, 2000). Willmott (2000) argued that the medical establishment has sequestered death in contemporary Western societies, and our experiences of health (e.g., how to acquire it) and illness (e.g., how to avoid it) are moulded by a science-informed medical discourse. With the rise of secularisation, and declining recourse to traditional religious beliefs about an ‘after life’, attention has become focused on the ways and means of preserving and extending life (Willmott, 2000). Transplantation, sited firmly within the private medical gaze, has become established as a viable method of warding off impending death for those with end-stage organ disease. As such, it is a treatment that they must seriously consider if unfortunate enough to experience organ failure. However, what of the psychosocial implications for those who give or receive an organ? Transplantation raises a number of ethical questions for these individuals and for all those in societies where the study of transplantation is undertaken and where this treatment is applied.

Questions have been posed about the way in which we might best conceptualise organs for transplant, with three metaphors (i.e., gift, resource, and commodity) detected in current thinking about transplantation (Svenaeus, 2010). Svenaeus (2010) argued that
‘gift’ is the sanctioned metaphor for donating organs, emphasising the need for donations to be altruistic and unpressured. However, within the medical establishment and other institutional authorities, organs are also understood as a resource, as evidenced by organ donation laws in many countries that are based on presumed consent from brain-dead patients. Organ procurement policies and practices transform bodies into a highly valued resource in the socio-medical sense (Sharp, 2001), and access to organs via living suppliers (e.g., the ‘desperately poor’) within a highly organised global trafficking network has also led to organs becoming highly valuable commodities in the socio-economic sense (Svenaeus, 2010).

The gift-of-life understanding of transplantation is so deeply embedded in transplant discourse it has the power to prescribe and direct the experience of donors and recipients (Shaw, 2010, 2012; Shaw et al., 2012). This understanding also gives rise to a ‘duty of care’, identified by Sothern and Dickinson (2011) as a means of repaying the debt that is incurred in the receipt of an organ. Gift-of-life discourse inevitably raises a range of questions associated with gratitude. For example, ‘should’ one be grateful? To whom ‘should’ one be grateful? How ‘should’ gratitude be expressed? How ‘should’ one live life post-transplant, recognising the magnitude of the gift received?

In this chapter I briefly outline the history of transplantation from the medical perspective and provide a ‘snapshot’ of recent Australian transplant data. This is followed with a review of the important ethical issues that are pertinent to transplantation, including: supply of organs, the definition of death as it relates to cadaveric donation; and the key issues of recipient selection, organ allocation, and social worth. Gift-of-life
discourse underpins all understandings of transplantation (Fox & Swazey, 2002), and I address the issue of transplantation with particular reference to this construct.

2.1 Transplantation: A brief history

The first human heart transplant took place on December 3rd, 1967 in Cape Town, South Africa. A media fanfare ensued with much attention given to the ‘miraculous’ nature of the procedure and God-like status attributed to Dr Christiaan Barnard, the surgeon who performed this ‘miracle’ (Moloney & Walker, 2002). The recipient, unfortunately, died 18 days post-transplant. In his outline of cardiac transplantation history, DiBardino (1999) noted that during the following twelve months, 102 heart transplants were performed worldwide. The quality of heart transplantation programs at this time was questionable though, and outcomes for recipients were far from positive (i.e., few of the 102 recipients survived). The problem of rejection, and limited knowledge regarding how to treat this, meant that many of these transplantation programs were closed. However, the introduction of ciclosporin as an immunosuppressant marked a turning point in heart transplantation, and annual rates of successful transplantation rose dramatically during the 1980s. Having achieved success in terms of immunosuppression, the paucity of organs available for transplant came into focus.

Although arguably the first organ transplant to capture worldwide attention, the heart was not the first organ to be transplanted. Watson and Dark (2012) outlined the early history of human kidney transplantation, reporting that the first human kidney transplant was conducted in 1936 in Kiev. Ukranian surgeon Yu Yu Voronory performed a series of six transplants on patients who had kidney failure as a consequence of attempted suicide by ingesting mercury. All six transplants failed and the patients died.
Improvements in surgical techniques and increased knowledge of the immune system (and its implications for transplantation) followed, and surgeons Joseph Murray and John Hartwell Harrison, along with nephrologist John Merrill, performed the first successful human kidney transplant in Boston (USA), in 1954. The transplant was between identical twins, thereby avoiding the problems encountered thus far with immune response (Murray, Merrill, & Harrison, 1958), and the recipient lived for a further eight years. Deceased kidney donor transplantation did not occur until 1964, when further advances in immunosuppression had been accomplished.

A liver transplant is more technically challenging than a kidney transplant, and it therefore took longer to establish successful liver transplantation (Watson & Dark, 2012). Thomas Starzl performed the first human liver transplant in 1963, and it was 1967 before a patient survived one year post-transplant. Liver transplantation remained experimental across the following two decades. As was the case with other forms of transplantation, the discovery of ciclosporin’s immunosuppressant properties in the mid-1970s dramatically increased the success of liver transplantation (as evidenced by recipient survival). In the 1980s, liver transplant became established as standard clinical treatment for end-stage liver disease (Watson & Dark, 2012).

Living donor liver transplantation (LDLT) emerged more recently as a clinical option for end-stage liver disease. The first successful LDLT was performed in Australia in 1987, between a mother and her child (Strong et al., 1990). Florman and Miller (2006) stated that live donor liver transplantation “is a tour de force both technically and ethically. It is a necessary evil . . . and an important option” (p. 508). They argued that the procedures involved are considerably more complex and demanding than in the case of
cadaveric donor transplantation. The first adult-to-adult LDLT was performed in 1993 but LDLT was mainly restricted to children throughout the 1990s because grafts that could be taken safely from live donors were too small to meet the metabolic demands of adult recipients (Sugawara & Makuuchi, 2004). Sugawara and Makuuchi (2004) reported that several different graft types have been developed in response to this problem, and this has contributed significantly to better (adult) patient outcomes.

Acquiring suitable donor organs has been a persistent challenge for all transplant communities from the outset of transplantation (Watson & Dark, 2012). The source of organs has been an issue of significant ethical concern, and it is to this (and other ethical issues) that I now turn.

### 2.2 Transplantation in Australia

All information contained in this section has been obtained from the Australian and New Zealand Organ Donation Registry (ANZOD, 2013), 2013 Annual Report, which is based on data collected from 1st January to 31st December 2012. These data provide an indication of the current state of transplantation in Australia, and also places the experience of transplantation in context.

#### 2.2.1 Donation and transplantation

Donation rates increased slightly from 15.1 deceased organ donor per million population (dpmp) in 2011 to 15.6 dpmp in 2012. ANZOD provided comparative donation rates with 40 other countries, and Australia was twentieth on this list. Croatia had the top donation rate of 36.5 dpmp, and Spain was second with 35.1 dpmp. The rate for the USA was 32.9
dpmp; for the UK was 18.3 dpmp; and for New Zealand was 8.6 dpmp. Japan and Bulgaria had the lowest rates with 0.9 dpmp and 0.3 dpmp respectively.

Most cases in which organs are made available result in a successful transplant. In 2012, only 12 of 354 donations did not result in successful organ transplant. The total number of organs transplanted was 1110: 607 kidneys; 230 livers; 72 hearts; 4 heart-lungs; 144 lungs; 38 pancreases; 4 pancreas islets; and 1 intestine. The total number of recipients was 1053.

### 2.2.2 Donor death

Among the donor population, cerebrovascular accident (CVA) has been an increasing cause of death since 1989, while road trauma has been on the decrease. From 2008 – 2012, CVA accounted for 49% of donor deaths, and road trauma accounted for 12%. CVA was the highest cause of donor death in both the ’35-54’ and ‘55 years and older’ age groups (67 deaths and 92 deaths respectively). The highest cause of death in the ‘0-14’ age group was Hypoxia–Anoxia (6 deaths). This was also the leading cause of donor death in the ‘15-34’ age group (24 deaths). Trauma (road) followed closely in this age group (22 deaths).

### 2.2.3 Waiting lists

The ‘active’ waitlist for kidney and liver transplants was slightly lower at the end of 2012 than at the beginning of the year, and the heart waitlist remained the same (see Table 1 below). While 945 (kidney, liver and heart) transplants were conducted during the year, 1106 patients were added to the list during the same period. Not included in the table, are
a further 237 kidneys (from living donors) transplanted in patients who were not on the transplant waitlist (ANZOD, 2013).

Table 1

*Organ Waiting Lists, Australia, 2012*

<table>
<thead>
<tr>
<th></th>
<th>Kidney*</th>
<th>Liver</th>
<th>Heart</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active at start of year</td>
<td>1299</td>
<td>192</td>
<td>78</td>
</tr>
<tr>
<td>New listings</td>
<td>651</td>
<td>347</td>
<td>108</td>
</tr>
<tr>
<td>Removed from list</td>
<td>160</td>
<td>60</td>
<td>15</td>
</tr>
<tr>
<td>Transplanted (Deceased donor)</td>
<td>533</td>
<td>268</td>
<td>85</td>
</tr>
<tr>
<td>Transplanted (Live donor)</td>
<td>59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transplanted Overseas</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Died on list</td>
<td>7</td>
<td>29</td>
<td>8</td>
</tr>
<tr>
<td>Active at the end of the year</td>
<td>1190</td>
<td>182</td>
<td>78</td>
</tr>
</tbody>
</table>

Note. Adapted from the 2013 ANZOD Annual Report, 07 – Waiting List, Organ Waiting Lists in Australia and New Zealand.

*The data included for the kidney waitlist is for 2010. This is included in the 2013 ANZOD Annual Report as the most recent data available.

The continuing disparity between supply and demand can be seen in Table 1. More patients were added to each of the waitlists than received transplants, and some patients (in each of the transplant groups) died while waiting for an organ to become
available. The Organ Waiting Lists Report (ANZOD, 2013) indicated that waiting list data do not reflect accurately the demand for transplantation, as many patients who would benefit from a transplant do not make it on to the waitlist.

2.2.4 Organ donation

Intensive Care Clinicians and Registrars were those who most often requested authorisation for organ donation (i.e., this occurred in 65% of cases). One hundred families (i.e., 31%) volunteered authority for donation, and 77 donors (i.e., 22%) had indicated their intention to donate on their driver’s license. Detailed below in Table 2 is the pathway following request for organ donation.

Not all retrieved organs are transplanted. Organ donation may not proceed for a number of reasons, and examples outlined in the report include: the organ being medically unsuitable, disease of the organ, extended ischaemic time, malignancy, IV drug use, logistics, and withdrawn consent.

Table 2

Outcome following request for organ donation, Australia, 2012

<table>
<thead>
<tr>
<th></th>
<th>Kidney</th>
<th>Liver</th>
<th>Heart</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requested</td>
<td>690</td>
<td>334</td>
<td>258</td>
</tr>
<tr>
<td>Consent Given</td>
<td>688</td>
<td>329</td>
<td>247</td>
</tr>
<tr>
<td>Retrieved</td>
<td>636</td>
<td>218</td>
<td>77</td>
</tr>
<tr>
<td>Recipients</td>
<td>607</td>
<td>230</td>
<td>76</td>
</tr>
</tbody>
</table>

Note. Adapted from the 2013 ANZOD Annual Report, 03 – Pathway to Organ Donation, Pathway of Organ Donation in Australia and New Zealand.
2.3 The ethical practice of organ transplantation

Ethical issues are inherent in the application of any sophisticated bio-technology (Kutner, 1987; Walker, 2009), and transplantation has given rise to a particularly diverse range of issues. As noted by Jonsen (2012), “almost as soon as successful transplantation was achieved, ethical problems were noticed lurking in the miracle” (p. 264). Although the ethical issues involved in transplantation are many and varied, most debate has centred around a few key issues, namely: what constitutes clinical evidence of death in the case of cadaveric donors; obtaining consent for donation without coercion of family members (in the case of both living and cadaveric donors); and ‘fair’ selection of recipients (Dubois & Anderson, 2006; Jonsen, 2012; Schmidt, 1998; Thomas, 2012; Truog & Robinson, 2003).

Technological advances in the field of transplant medicine are occurring so rapidly that concern has been raised about medical and legal policies and practices being formulated prior to consensus being reached on ethical issues (Sharp, 1995). Furthermore, beyond the ethical issues raised in discussing organ transplants, there is the broader issue of how healthcare resources are best directed. Organ transplantation is an expensive treatment, and some have questioned the appropriateness of publicly funding expensive technologies that benefit only a few, when many more might benefit from a broader distribution of these resources (e.g., Kuder & Roeder, 1995; Kutner, 1987; Robinson, Williams, Dickinson, Freeman, & Rumbold, 2012).

2.4 Organ scarcity

Advances in the field of medicine (e.g., immunosuppression, surgical techniques, prevention of infection) have led to increasing rates of successful transplantation, and concomitant increases in the demand for transplantation. Indeed, transplant medicine is
now a victim of its own success in that the issue of supply and demand has reached what Sharp (2006) deems to be a crisis point. She argued that transplantation is increasingly being understood as a basic medical right in the US (and countries that have similar transplant policies). As national waitlists have lengthened, the realm of transplantation has become beleaguered by intense ‘scarcity anxiety’. That is, alarm and desperation, elicited by the seemingly ever-widening gap between supply and demand (Sharp, 2006).

Ethical issues in conducting transplantation can be considered in terms of two main groups: those concerning (potential) donors and those concerning (potential) recipients.

2.4.1 Potential donors: Organ procurement

The short supply of organs is a persistent problem in transplantation, and increasing the level of organ procurement is essential if the possibility of transplantation is to be offered to the growing number of those who require this treatment. To this end, options for increasing the availability of organs that were once perceived to be abhorrent (e.g., payment or financial incentives for organs) are now being considered (Sharp, 2001, 2006). Rates of organ trafficking and tourism, where prospective recipients travel to countries in which organs can be purchased, are rising (Budiani-Saberi & Delmonico, 2008). As part of their work for The Transplantation Society (TTS) and the World Health Organization (WHO), Budiani-Saberi and Delmonico (2008) reported that thousands of transplants are being conducted annually across Pakistan, the Philippines, Egypt and China – with recipients from Saudi Arabia, Taiwan, Malaysia, and South Korea, and also (though in smaller numbers) from Australia, Japan, Oman, Morocco, Canada and the United States. They estimated that 5-10% of worldwide kidney transplantation is being conducted via the organ trade.
Establishing non-coerced consent (either from donors or donor families) is of utmost importance in the context of organ donation, and this becomes a particularly sensitive issue when the options of payment or financial incentives are introduced. Arguments in favour of the commercialisation of transplantation construct this option as a win-win situation, where a vendor exercises his/her right to sell an organ, and a recipient receives the organ he/she needs (Moazam, Moazam, & Jafarey, 2009). However, Moazam et al. (2009) have challenged these arguments, emphasising that they are largely reductive and utilitarian in nature and, as such, are misleading. Vendors tend to be among the most socioeconomically disadvantaged of people and the extent to which non-coerced consent is achieved in this context has been questioned (Scheper-Hughes, 2001). The current debate regarding commercialisation is based on philosophical and legal principles that fail to acknowledge the social and economic realities driving these donor-vendors to sell their kidneys (Moazam et al., 2009).

A further, and also contentious, supply of organs for transplant is from executed prisoners. This practice is condoned in countries such as China, where reports have indicated that approximately 5000 organs are acquired annually from executed prisoners (Westall, Komesaroff, Gorton, & Snell, 2008). Westall et al. (2008) considered some of the ethical, medical and legal concerns associated with the transplantation of organs from executed prisoners. For example: the difficulty of ensuring that consent, given in the context of imminent execution, is free from coercion; the risk of corruption in the judicial system, such that executions are conducted with the specific aim of obtaining organs; the high prevalence of infections such as hepatitis and HIV in organs transplanted overseas,
suspected of coming from executed Chinese prisoners; and Australian ‘transplant tourists’ receiving publicly-funded treatment for their ongoing medical problems when they return.

Another means of increasing the supply of organs for transplant might be to introduce an opt-out system of organ donation. As opposed to an opt-in system where explicit consent for donation is required, consent is ‘presumed’ in an opt-out system (unless a person specifically registers to opt-out). In their study of the role of the ‘no-action default’ in increasing the number of potential donors, Johnson and Goldstein (2004) found that when organ donation is the default option (as it is in an opt-out system), the rate of organ donation increases. The Australian government has considered the possibility of introducing an opt-out system but the implementation of such a system has been postponed (Delvriviere & Boronavskis, 2011). In their discussion paper presented to the Western Australian parliament, Delvriviere and Boronavskis (2011) noted:

It is essential on this matter to understand that people opposing organ donation are a small but very vocal group. Their ability to steal the debate from a law that would suit the majority of the population has to be perceived and made relative. We should strive to develop a true Western Australian community vision of participating in life giving, life enhancing activities. This initiative should be to build and strengthen our community values (p. 21).

Once firmly established boundaries are now giving way to the demand for transplantable organs (Ohler, 2001). The idea of payment/financial incentives for organs and/or the use of organs from executed prisoners remains contentious, and has evoked considerable debate across a range of medical, political and academic forums (Amaloraparvanathan, 2007; Bryce et al., 2005; Chkotua, 2012; Kishore, 2005; Rothman
& Rothman, 2006; Satyapal, 2005; Schweda & Schicktanz, 2009; Westall & Snell, 2007). However, arguments in favour of utilising these methods of organ procurement are gaining ground (Cameron & Hoffenberg, 1999; Clark, 2006; Westall et al., 2008).

Cameron and Hoffenberg (1999) posited that Western opinion and debate, thus far, can be understood as “kneejerk reactions from a Western viewpoint . . . generated post hoc to justify initial reactions” (p. 728), lacking in moral imperative. They cautioned against cultural imperialism, in the context of transplantation, and suggested that it ‘should’ be possible to minimise exploitation and risk while maximising benefit for the most needy (i.e., prospective recipients).

2.4.2 Cadaveric donation, and ‘the problem of death’

In the case of cadaveric donation, patients must be declared dead before organs can be retrieved for transplantation (i.e., the ‘dead-donor rule’). How death is ascertained in this context, though, has been the subject of contention. The development of new technologies (e.g., mechanical ventilation and cardiac support devices) has complicated understandings of death, previously determined by the cessation of circulation, respiration and neurologic functioning (Truog & Robinson, 2003).

The definition of brain death (i.e., deemed to be irreversible loss of function of the entire brain, in the US; or loss of brain stem function, in the UK) suggests that death can occur even while circulation and respiration is maintained. This distinction between brain death and cardiovascular death has generated considerable controversy since its proposal by the Ad Hoc Committee of Harvard Medical School in 1968 (Dubois & Anderson, 2006; Thomas, 2012). Truog and Robinson (2003) have argued that ‘brain death’ is a social construction designed with the explicit purpose of meeting the needs of the
‘transplantation enterprise’: that is, in order to circumvent the dead-donor rule and remove organs from heart beating donors.

The concept of brain death is critical to practices of organ retrieval, where continued circulation and respiration is necessary to avoid the damage caused when blood supply is cut off (Sharp, 2001). End-of-life technologies blur the distinction between life and death, leading to confusion and conflict among the general public (e.g., donor and potential-donor families) concerning brain death and its implications (Kulkarni & Cronin, 2006; Long, Sque, & Addington-Hall, 2008a; Siminoff, Gordon, Hewlett, & Arnold, 2001). Despite brain death being accepted as standard practice in the context of organ transplantation, universal agreement as to what constitutes brain death has still not been achieved among healthcare professionals (Long, Sque & Addington-Hall, 2008b; Truog & Robinson, 2003). Further, Long et al. (2008b) posited that brain death raises the potential for moral conflict among these healthcare providers who must confront the ‘dark side’ of organ transplantation. That is, they must treat dead people as if they are still alive, continuing to provide “intensive and intimate medical care” in order to procure viable organs (p. 260).

The number of organs available for transplant after brain death is declining. This is due to a number of factors, including injury-prevention strategies (such as seatbelts and airbags in cars) and improvement in treatments for brain injury (Bell, 2006). Non-heart-beating donation (i.e., donation after cardiac death) was general practice before the introduction of brain death criteria and because of advances in medical technologies (e.g., organ preservation, transplant surgery, immunosuppressive techniques) it is now re-emerging as a method by which the cadaveric donor pool might be increased (Kerridge,
Saul, Lowe, McPhee & Williams, 2002; Kumar, Shekar, Widdicombe, & Fraser, 2012). However, as noted by Long et al. (2008a), a diagnosis of cardiac death in this context is not ethically unproblematic; heartbeat and respiration cease, but only for a short time (guidelines vary but some stipulate as little as two minutes). Perfusion (with preservation fluid), to maintain organ viability, follows quickly and this can trigger cardiac and/or neuronal activity. Bell (2006) reported the understanding that although the cessation of circulation and respiration indicate death, they only do so when they have ceased long enough for the brain to die (i.e., a person is dead when his/her brain is dead). He raised the question; if neuronal activity can be triggered by perfusion, and patients in these circumstances have not been diagnosed dead by brain death criteria, are they indeed dead? Bell suggested that diagnosis of death in the context of transplantation is a vexing problem, with significant clinical and ethical implications, requiring much more than ‘simplistic legislation’ to resolve.

2.4.3 Recipient selection, organ allocation, and social worth

Advances in surgical techniques and knowledge of immunosuppression have led to expanded selection criteria, and transplantation is now a potential option for those who would not have been considered previously because of significant medical risk (Varekamp, Krol, & Danse, 1998). This has added to the demand for organs, and made organ allocation a considerably more complex process.

The Australian Medical Association (AMA, 2012) has provided guidelines that inform organ allocation decision-making. The most important principle suggests that organ allocation should be based on transparent clinical and ethical criteria, with no discrimination on the basis of social status, lifestyle, or behaviour. The following factors
were outlined as appropriate for consideration in the allocation of organs: relative severity of illness/disability, urgency of need, and time on waitlist; medical factors affecting likelihood of success; and likelihood that the recipient will comply with the necessary post-transplant treatment. Jonsen (2012) posited that even though organs are ostensibly distributed on the basis of medical need, and with explicit selection criteria in place, “there is much room for clinician bias” (p. 267). This is, he argued, particularly so when it comes to assessing prospective recipients’ likelihood of complying with post-transplant treatment.

Like the issues of organ supply and definitions of death, those of recipient selection (i.e., waitlisting) and organ allocation stir vigorous debate. Childress (2001) outlined the three general criteria utilised when waitlisting patients and/or allocating donated organs. These are patient need, probability of successful outcome, and time on the waitlist. He noted that although the relevance of these criteria is generally accepted, debate is encountered when attempting to specify and ‘weight’ their importance. Schmidt (1998) argued that it is difficult to ensure equitable access to waitlists as, although rationalised in medical terms, most of the criteria on which recipient selection is based, are largely non-medical (and discretionary) in nature.

Non-compliance with treatment, such as drug regimens, is a major contraindication for all forms of transplantation. Non-compliance, though, is a behavioural characteristic, and one that is difficult to measure. Schmidt (1998), like Jonsen (2012), argued that there is much room for bias on the part of healthcare professionals in this context. That is, much rests on ‘subjective’ variables (e.g., the experience of healthcare professionals, and/or ‘the impression’ the patient leaves on
them) when it comes to assessing non-compliance. Social contraindications (i.e.,
behaviours, such as alcoholism, that “are not just detrimental to one’s health but also
widely viewed as morally reproachable”; p. 55) were also of interest to Schmidt. He
posited that one of the difficulties encountered in assessing this type of behavioural
criterion is separating medical need from social stigma. He noted, for example, that few
alcoholics receive a transplant although, theoretically, they should represent the largest
group of liver recipients, as alcoholism is the leading cause of liver failure. He found that
doctors dismissed the possibility of moral judgment when accounting for the low rate of
liver allocation to alcoholics. These doctors claimed that post-transplant non-compliance
is widespread among this population (even though, Schmidt noted, there is little evidence
to support these claims).

With regards the ethics of social contraindications, Kluge (1994) argued that
lifestyle considerations should be used as a criterion for the ethical distribution of the
scarce organs available for transplant. He posited that ‘inappropriate’ lifestyle choices are
exactly that, choices, and when individuals choose to smoke or drink alcohol excessively
they do so in the knowledge that it will damage their health and lead to the need for
healthcare at some time. He argued that alcohol abusers, for example, have acted
irresponsibly and providing them with the same claim to a liver transplant as those who
have acted responsibly is an “unjust act”, a violation of the principle of equality and
justice: “if others die because alcohol abusers have received the available livers, the
blame will lie not only with alcohol abusers but also with those who insist on treating
alcoholics the same as responsible persons” (p. 746).

The general public hold a negative perception of those believed to have caused
their own illness, and is often willing to discriminate against them (Hyde & White, 2009, 2010; Neuberger, Adams, MacMaster, Maidment, & Speed, 1998; Rodrigue, Hoffman, Park, & Sears, 1998; Sears, Marhefka, Rodrigue, & Campbell, 2000). In scenario-based studies concerned with the allocation of donated livers (e.g., Ratcliffe, 2000; Wittenberg, Goldie, Fischhoff, & Graham, 2003), the majority of participants showed preference to those with naturally occurring liver disease above those with alcoholic liver disease. Thirty five per cent of participants in the Wittenberg et al. study allocated no donated livers to patients with alcoholic liver disease. Ubel et al. (2001) also addressed the issue of judgment in their scenario-based study of organ allocation. In their sample of prospective jurors, participants allocated only 33% of organs to those who engaged in unhealthy behaviours, and significantly fewer to those who were deemed responsible for causing their disease. In a similar scenario-based study, Ubel, Baron and Asch (1999) found that social desirability judgments were evident in decision-making (i.e., allocation of organs) in a community sample. They argued that this outcome could not be explained, alone, by the perceived personal responsibility (for illness) of prospective recipients or their more negative transplant prognoses. Instead, those who engaged in socially undesirable behaviours were understood as being “simply less worthy” (p. 58). They went on to postulate that the outcomes of their study suggest social worth judgments “may be lurking in the background of many otherwise plausible arguments” (p. 68).

Age is as another ambiguous criterion in the selection of recipients and allocation of organs. Age can be medically relevant but a bias against older adults is not isolated to medical reasoning; it represents a social and moral bias towards giving priority to the young (Schmidt, 1998). Others have shown that age is an important criterion where the
distribution of health benefits is considered (e.g., Browning & Thomas, 2001; Dolan, Shaw, Tsuchiya, & Williams, 2005; Tsuchiya, 1999; Varekamp, Krol, & Danse, 1998). Varekamp et al. (1998) investigated the role of age in decisions about scarce health resources in a sample of nephrologists, surgeons, immunologists, nurses, social workers, and others working in the transplant field. They found that age influenced both selection of patients (for waitlisting) and allocation of organs, though in a covert, implicit manner. In a community sample, Browning and Thomas (2001) also found that recipient age was one of the most influential factors in priority ranking for organ allocation. Their findings indicated a bias against older people; seven of the top 8 rankings were those involving younger people. Also, 65.5% of respondents indicated that younger people should receive priority over those who are older.

Worthiness and recipient-age are relevant to community preferences for the allocation of organs (Tong et al., 2010). In a systematic review of 15 studies, including more than 5563 participants, Tong et al. (2010) identified seven themes: maximum benefit (attempts should be made to achieve maximum health gain. This involves assessment of patient survival and quality of life, with recipient prognosis being an important consideration in determining this); social valuation (organs should be allocated on the basis of societal gain or utility, with higher priority given to patients with dependents, especially those with young children); moral deservingness (judgments are made about patients’ worthiness, with lower priority given to those who engage in socially undesirable behaviours such as smoking, crime and/or alcohol/drug abuse); prejudice (access to transplantation denied on the basis of country of origin); fair innings (priority for younger patients shown across all studies); first come, first served (preference shown
for patients who have been on the waitlist for the longest time); and *medical urgency* (preference shown for those in greatest need). Tong and her colleagues reported that a lack of transparency on the part of the medical community has given rise to public scepticism about the ‘fairness’ of organ allocation. Their study, though, did not provide evidence of a general consensus among the wider community (e.g., some community members gave priority to those on the waitlist for the longest time, while others gave priority to those in ‘urgent’ need of a transplant). Tong et al. argued that organs for transplant are a community resource and, as such, community members should not be excluded from the ongoing development of allocation policy.

Urgency, one of the themes identified by Tong et al, (2010) as being relevant to organ allocation, is also one of the criteria addressed by Schmidt (1998). Schmidt noted that in some transplant centres patients classified as being in ‘urgent’ need of a transplant are exempted from allocation rules and receive priority. He highlighted the broad understanding of urgency that can be applied in this context, to include medical, psychological and/or social conditions. For example, medical urgencies arise when a patient can, for physiological reasons, no longer be treated with dialysis. Psychological urgencies refer to the suffering and anguish that might arise in the context of long-term dialysis and their side effects (e.g., where patients might experience depression and suicidal ideation). Social urgency arises when the welfare of others is affected by a patient’s illness. Schmidt cited the case of a mother who is no longer able to care for her children, and also noted other ‘outstanding’ roles that might be included in this category (e.g., employers and political leaders). He argued that considerations of urgency “invite subjectivities, and manipulations of various kinds, because no objective, generalizable
parameters exist with which different degrees of suffering can be measured” (p. 68).

Social urgency was highlighted as being of particular concern as it is the type of criterion that might arguably most influence transplant team evaluations of social worth and underservingness. This, he argued, is highlighted in the case of homosexuals, prostitutes and welfare recipients who were unable to access dialysis treatment in the 1960s and 1970s.

The scarcity of organs available for transplant has exacerbated many of the ethical dilemmas outlined above. The scarcity of organs also underpins the idea that donated organs are a rare and highly precious ‘gift’ (i.e., the gift of life), and gift-of-life discourse has become the dominant discourse in the realm of transplantation. It is to gift-of-life understandings of transplantation that attention is now turned.

2.5 Organ transplantation: The gift-of-life?

In the context of organ transplantation, the gift-of-life metaphor is based on the premise that a donated organ represents life itself, given - gifted - by the donor to the recipient. Sharp (2001) posited that it is aimed at metaphorically reworking human organs and the practice of transplantation (i.e., the taking of an organ from one person’s body and placing it in the body of another) such that the reality of the organ’s origin is obscured, or imaginatively ‘mystified’, and the ethical/moral unease associated with the practice of transplantation is thus quelled. Gift-of-life is the sanctioned metaphor of organ donation (Svenaeus, 2010), with all transplantation discourses (i.e., ideology and practice) founded on it (Fox & Swazey, 2002). Siminoff and Chillag (1999) argued, as have others (e.g., Lauritzen, McClure, Smith, & Trew, 2001; Shaw, 2010; Shaw et al., 2012; Sothern &
Dickinson, 2011), that the scarcity issue underlies the ubiquitous use of the gift-of-life metaphor across donation campaigns (with a view to increasing donation rates) and healthcare settings (with a view to ‘enforcing’ recipients’ compliance with immunosuppression regimens and other post-transplant treatment). They questioned the legitimacy of gift-of-life discourse, stating that it “rests on a fallacy about gift giving and, in particular, about ‘acts of charity’” (p. 35).

Although developed in the context of preindustrial societies (such as the American Northwest, Melanesia, and Polynesia) by anthropologist Marcel Mauss, gift exchange theory (GET; Mauss, 1970) is routinely utilised as a framework for conceptualising the exchange that takes place in the context of transplantation. Sque and Payne (1994) described gift exchange as an ancient form of (money-less) economy, where gift giving entails a social contract based on three principles: the obligation to give; the obligation to receive; and the obligation to reciprocate. They reported that some have questioned the utility of GET in the context of contemporary market-driven societies, where economies are based on the impersonal, often anonymous, exchange of money rather than on the interpersonal exchange of gifts that defined obligation and bound individuals to each other in archaic societies. They, along with others (e.g., Fox & Swazey, 2002; Gill & Lowes, 2008; Parsons, Fox, & Lidz, 1972; Sharp, 2006) have argued, though, that as organ donation does not involve a monetary transaction (this practice being illegal in most developed countries at the present time), sociologically and psychologically, donated organs can be thought of as gifts in the Maussian sense.

Accepting that donated organs can be understood as gifts, what then of the supposedly ‘free’ gift and the three interlocking principles (to give, to receive, and to
reciprocate) on which gift exchange is premised? Fox and Swazey (2002) suggested that although the organ donation system is founded upon the tenets of voluntarism and altruism, the perception of gifts (i.e., organs) freely given and freely received is erroneous. Cultural mores suggest that if the relevant circumstances present themselves, the (morally) correct response for potential donors’ families is to give. Similarly, the immense need of the potential recipient - in many cases, he/she will die if an organ does not become available - means that the person is obligated to receive an organ if one is offered. This leaves the obligation to reciprocate, arguably the most problematic feature of the gift-of-life metaphor (and gift exchange understandings of transplantation). Having received the gift-of-life, a rare and precious gift of inestimable value, the recipient must reciprocate in order to fulfil the terms of the social contract into which he/she entered upon receiving the gift. In the case of cadaveric donation, the donor of the organ is no longer alive, and the debt incurred via the receipt of the gift cannot be directly repaid. Although some actions, such as expressing gratitude to the donor family and/or helping others through support groups, might go some way toward alleviating the sense of indebtedness, none of these is likely to be understood as sufficient reciprocation for the priceless gift received. This may be onerous and give rise to the ‘tyranny of the gift’; a phrase coined by Fox and Swazey (2002) to describe the high psychological and moral burden experienced by those who believe they are unable to reciprocate appropriately, given the magnitude of the gift received in organ transplantation.

In receiving a transplanted organ, recipients are culturally compelled to take on the obligation to reciprocate. Sothern and Dickinson (2011) explored the ways in which this obligation manifests in recipients’ lives, particularly given that transplantation does
not return them to a state of ‘perfect’ health, but rather represents the trading of one set of health problems (i.e., those associated with organ failure) for another (i.e., those associated with immunosuppression). They posited that, by virtue of organ scarcity (and therefore the value inherent in ‘the gift’), recipients are compelled to assume practices of self-care that are, in effect, a form of reciprocation (i.e., an appropriate ethical/moral response for the gift received): “the recipient is not a passive receiver of the gifted organ but rather one who must carefully construct their post-transplant life to ensure that these rare gifts are not wasted” (p. 891).

The definition of ‘care’ is important in the context of Sothern and Dickinson’s (2011) study. They defined care as a relational practice: not one that is offered ‘to’ someone or done ‘by’ someone, but rather a shared accomplishment that involves others (including unknown others), institutions and technologies in complex (i.e., interdependent, reciprocal, and multidirectional) relationships. They studied self-help and autobiographical texts developed for the specific consumption of transplant recipients (both pre- and post-transplant), and found that these texts prescribed the experience of transplantation to a large extent. This was particularly evident in the key theme of many of the texts: performance of the ‘good recipient’ (or ‘good prospective recipient’), and its importance. They reported, for example, that these texts outline how decision-making, in terms of recipient selection (wait-listing), is not a purely objective matter: readers are advised that while selection might appear objective (i.e., based on medical criteria), the transplant team must evaluate a patient’s chance of success, and there is a particular focus on the likelihood that he/she will comply with post-transplant medical treatment. This evaluation is a subjective decision, based on how ‘good’ the patient is (e.g., his/her
compliance with pre-transplant self-care routines) in the opinion of all those who make up the transplant team. These texts, Sothern and Dickinson posited, define practices of self-care as the duty of the recipient. They suggest that such practices are owed to the broader community, including the donor/donor family, prospective recipients, those who will not ever receive an organ, healthcare professionals, and all of the various ‘systems’ entailed in transplantation. By complying, the recipient demonstrates both worthiness of, and reciprocity for, the gift received. This prescribed (i.e., ‘right’) way of caring for the gift does not allow for the full scope of the transplant experience to be acknowledged by the recipient.

Gift-of-life discourse is ubiquitously applied in the realm of transplantation. The relevance of this discourse, as it pertains to the experience of critical care specialists and donor/recipient coordinators in the New Zealand context, was the subject of research conducted by Shaw (2010). Acknowledging the widespread application of gift-of-life discourse in this context (with the underlying motive of increasing donation via its promotion as a noble act of significant moral worth), she found that it conflicted with the experience of the healthcare professionals in her study. Critical care specialists reported that although gift terminology might be acceptable in public settings (e.g., as a means of distinguishing the altruistic act of donation from a more commercialized ‘trade’ in human body parts), it over-simplifies what transpires in the transfer of an organ from one person to another, and the use of gift terminology in the context of critical care (e.g., when approaching families to discuss donation) was inappropriate. Shaw argued that gift-giving, as an artefact of contemporary consumer culture, is often superficial, superfluous
and fungible, and she proffered the concept of ‘sacrifice’ as a more adequate representation of organ transfer:

This raises the question of whether we should expose the illusion of the gift and name it publicly as sacrifice. This would not only entail revelation about the painful experience of organ donation for relatives of deceased donors and some health professionals, but also acknowledge gift rhetoric and efforts to solicit altruistic tissue donation as fraudulent transactions, already implicated in marketplace exchange. (p. 614).

Gift discourse fails to capture the broad range of psychosocial and cultural complexities of organ transfer, and Shaw questioned the ethics underlying the appropriation of a term that does not accurately reflect the phenomenon it purportedly represents.

Gift rhetoric is neither apolitical nor neutral (Shaw et al., 2012). In their study of New Zealanders’ experiences of transplantation and understandings of bio-identity, Shaw et al. (2012) found conflicted responses to the concept of the gift, with many participants reporting ambiguity in relation to it. Through the gift-of-life metaphor, organ recipients are ‘manipulated’ via the constant reminder of how lucky they are to have received such a rare and precious gift. Shaw et al. found that recipients felt compelled to repay the gift. Attempts at reciprocation took many forms, including remembering and thanking donors privately and/or in public Thanksgiving services, sending gifts or letters to donors/donor families, participating in research projects, speaking to the media, or giving public lectures/talks. However, many struggled to reciprocate in a way they believed to be sufficient for the magnitude of the gift received.
A ‘moral economy’ operates as a form of social control in the context of transplantation, where recipients are constantly reminded that they have a duty of care for the gift (Shaw et al., 2012). In the Shaw et al. (2012) study, evidence of ‘deserving recipient’ status was found to be important, and some recipients undertook stringent programs of self-care as proof of their deservingness (i.e., they were doing all that was possible to ensure that the precious gift they had received was not ‘wasted’). Although gift-of-life discourse undergirds transplantation and (in large part) directs the experience of it, Shaw et al. argued that it does not always, adequately or accurately, reflect the experiences of those directly involved.

In a study exploring the anonymity protocol and non-reciprocity rule that are part of the transplantation protocol in New Zealand, Shaw (2012) noted the inconsistencies of the gift trope in this context. The altruistic gift (i.e., free and unconditional) is conflated with that of the Maussian gift (where the gift represents the initiation and perpetuation of ongoing relationships). Findings with regard to the anonymity protocol were inconclusive, with indications that some recipients might benefit from a relaxation of the rules, while others might become overwhelmed by the obligation to reciprocate. Shaw’s research highlights the extent to which gift rhetoric engages organ recipients in a prescribed experience of transplantation. Moral work is circumscribed as the recipients manage their emotions, particularly in public where they must adhere to scripts (i.e., “sanctioned forms of storytelling”; Sharp, 2006, p. 157) that cleanse the transplantation experience of its more troubling aspects.
2.6 Quality of life post-transplant

Recipients are expected to live their lives post-transplant in a way that pays tribute to the gift they have received. However, despite the many allusions to new life and re-birth within the gift trope, organ recipients seldom re-emerge into the world ‘fixed’, with a clean bill of health. While wider society may be given to believing that the transplanted organ represents a panacea for all the recipient’s ills, research has indicated that the process of transplantation is itself implicated in the development of a range of diseases and disorders (e.g., Buell, Gross, & Woodle, 2005; Gottschalk, Rooney, & Heslop, 2005). In order to survive with a transplanted organ, recipients must take immunosuppressant medications and problems associated with these medications include, but are not limited to, an increased risk of: HEV (hepatitis E virus) infections (Pischke et al, 2012); hypertension, hyperlipidemia, renal dysfunction/failure, and diabetes mellitus (Hosenpud et al., 1999); and cancers such as lung, kidney, colon, rectum, pancreas, Hodgkin’s lymphoma and melanoma – with a five-fold, or greater, increase in the risk of developing Kaposi sarcoma, skin (non-melanoma), non-Hodgkin’s lymphoma, liver, anus, vulva and lip malignancies (Brennan, Rodeheffer, & Ambinder, 2012).

Research has also indicated that transplantation may be psychologically hazardous and result in recipients experiencing distress over an extended time period after their transplant surgery (Bunzel, & Laederach-Hofmann, 1999; Mai, 1993; Reyes et al., 2003; Triffaux et al., 2001). Dew et al. (2005) found that although distress for the majority of transplant recipients in their study was transitory, a significant minority experienced persistent distress linked to post-operative concerns (e.g., the development of diseases linked to immunosuppressant use). Recipient distress has also been attributed to the
challenge of coping with loss (i.e., of their own organ) and acceptance of a donor organ (Kaba, Thompson, & Burnard, 2000). In their study of the psychological problems of heart recipients, for example, Kaba, Thompson, Burnard, Edwards and Theodosopoulou (2005) found the presence of ‘somebody else’s heart inside me’ was of critical concern to participants, who reported feeling anxious about the manner in which someone else’s heart might influence their own personality and change them in some way.

Many transplant patients experience debilitating psychosocial stressors, both pre- and post-transplant, that hold the potential to elicit high levels of anxiety and influence quality-of-life (QOL). These include: loss of work and associated financial independence; loss of autonomy, control and privacy; changing family roles; changes in lifestyle; concerns about ‘passing’ waitlist evaluations and making it on to the waitlist; relocation, in order to be close to transplant centres; fear of dying before a transplant becomes available; post-transplant adjustment in family roles; fear of organ rejection; health issues related to immunosuppression regimens; spousal or caregiver stress; sexual dysfunction; and concern about body image due to increased hair growth and/or weight gain (Engle, 2001). Anxieties may be further exacerbated when difficulties are not acknowledged. Engle (2001) posited that patients under-report psychosocial problems: pre-transplant, because of the fear of not being waitlisted; and post-transplant, because of gratitude (to the transplant team) and awareness that ongoing care from the transplant team will be needed.

The particular methods of evaluation utilised are an important factor contributing to the under-reporting of psychosocial problems in medical studies: the patient’s subjective experience is an important factor in QOL and well-being, and this is not...
considered in many current assessments. De Geest and Moons (2000) identified what they describe as a ‘blind spot’ in post-transplant QOL assessment. They argue that healthcare providers rely on objective criteria (e.g., measures of the side-effects of immunosuppressive regimens - such as hypertension, malignancies, diabetes, muscle weakness, increased hair growth, or brittle skin) to evaluate transplant recipients’ QOL, with little attention paid to the subjective experience of these symptoms and the level of distress they might cause. QOL assessments are critical to clinical trials and outcome studies of transplantation. However, a broadening of medical understandings of QOL is required: the inclusion of recipients’ subjective experience as a legitimate and valid component of evaluation is essential to a more comprehensive understanding of their quality of life (De Geest & Moons, 2000; Engle, 2001).

Some of the broader issues of post-transplant quality-of-life were noted by Crowley-Matoka (2005) in her exploration of kidney transplantation in Mexico. She found that for a number of sociocultural and political/economic reasons the desire for a transplant is not ‘automatic’ in this context. These reasons include, but are not restricted to: fear at the prospect of transplantation (particularly given the poor state of the health system where it is not unusual for hospitals to run short of dialysis supplies); scepticism and distrust of government-operated hospitals and the information/treatment options offered by healthcare providers in these institutions; and the requirement for a living donor – the dearth of cadaveric donation in Mexico means that patients typically have to approach a family member for a kidney. Crowley-Matoka found that desire for transplantation has to be fostered, and this is most often achieved by a restorative discourse, wherein transplantation is portrayed (by transplant coordinators, for example)
as the means by which patients will be able to resume a normal life. She noted that successful transplant in the Mexican context means more than just survival: for men it entails productivity and the ability to support their family; for women it entails reproductivity and the ability to have children.

Unfortunately, for many transplant recipients the expectation of returning to a ‘normal’ life is not met. Understandings of success in this context are problematized, and often deeply painful, as recipients come to realize that they have exchanged one set of hardships for another. Life post-transplant is one of ‘persistent liminality’; caught between health and illness; dependent patient and independent normal (i.e., productive/reproductive) person (Crowley-Matoka, 2005). As Crowley-Matoka (2005) stated: “[u]ltimately, the lived experiences of these patients reveal a much more contingent and often deeply-vexed version of the ‘gift of life’ and the possibilities for ‘health’ offered up by transplantation” (p. 822). Lives are extended by transplantation, but they are so radically altered in the process that often all thought of resuming a ‘normal’ life (as it was pre-illness) must be abandoned. The reality of life post-transplant is often juxtaposed to that ‘promised’ in gift-of-life narratives (Kierans, 2011), and it is difficult for recipients to openly acknowledge the negative aspects of transplantation given the enormity of the gift received (Sharp, 2006).

2.7 Conclusion

Transplantation is a sophisticated technology that re-crafts the bodies, and lives, of those who donate or receive an organ. It is also a transformative bioethical and biopolitical phenomenon that has evolved over a relatively short period of time from an experimental, wondrous and ‘miraculous’, procedure to one that is considered standard practice and a
medical right in many developed nations (Sharp, 2006). Though rapid, this development has not been trouble-free; transplantation is intensely problematic and rife with complexities. Of particular concern, is the difficulty encountered in defining success, and how one goes about achieving it. Is successful transplantation to be evaluated only in terms of lives extended? What of the physical and psychosocial costs to the recipient? What of these same costs to the donor?

The technical success of transplantation in terms of surgical technique and the ability to subdue the immune system is uncontested. However, such success has brought with it an exponential increase in the demand for transplantation, and the scarcity of available organs has become the most pressing concern in contemporary transplantation (Kishore, 2005; Jonsen, 2012). A number of measures have been considered in attempts to remedy this problem. Strategies include expanding donor criteria (DeLario, Quetschenbach, Croezen, Niedfeldt, & Landon, 2014), and payment for organs (Cameron & Hoffman, 1999; Moazam et al., 2009; Westall et al., 2008). Another of the main ethical concerns in transplantation, and one that is also undergirded by the scarcity issue, is that of recipient selection and organ allocation. Although strict guidelines are in place for both of these processes, it has been argued that much is left to the discernment of individual transplant centres (i.e., their varying philosophies and policies) and the healthcare professionals associated with them (Jonsen, 2012; Schmidt, 1998).

The gift-of-life metaphor undergirds all transplantation discourses (Fox & Swazey, 2002), and the issue of organ scarcity comes into play here too. Many (e.g., Siminoff & Chillag, 1999; Shaw, 2010; Shaw et al., 2012; Sothern & Dickinson, 2011) have argued that the scarcity of organs highlights how precious and valuable they are, and
gift rhetoric is ubiquitously utilised across institutional/healthcare settings with the aim of increasing donation rates and ‘enforcing’ recipients to take on stewardship of the gift. Gift-of-life understandings of transplantation are seen to be powerfully influential in the post-transplant experiences of organ recipients (Fox & Swazey, 2002; Shaw, 2010, 2012; Shaw et al., 2012; Sothern & Dickinson, 2011).

Unfortunately, for many recipients, the outcomes of transplantation are not entirely positive. The immunosuppression regimen they must undertake in order to survive with a transplanted organ has a host of negative side effects, and these have repercussions in terms of both physical and psychological quality of life. Life does not return to ‘normal’; at least not the pre-illness state of normal that many recipients believe to be the promise of ‘the gift-of-life’. As Crowley-Matoka (2005) found, transplant recipients may live in persistent liminality, where they are caught ‘betwixt and between’ the roles of healthy/independent/‘normal’ person, and those of ill/dependent patient. Given they have received the gift-of-life, though, it is not befitting for them to openly acknowledge the negative aspects of their experience. Kierans (2011) argued that a focus on the prioritised, and often sensationalised, issue of organ procurement disguises the suffering that takes place at both ends of organ transfer. This is particularly so for recipients, who often appear in transplant narratives as ‘the winners’. She calls for the development of a deeper and more inclusive understanding of transplantation. In answer to this call, my focus on the lived experience of transplantation, in the current study, enriches and extends the understanding of transplantation from the perspective of those most intimately involved; recipients and prospective recipients themselves.
CHAPTER THREE

Gratitude

“[M]etaphor establishes a storyline” (Frank, 1995, p. 57).

3.0 Introduction

In their investigation of gratitude as a human strength, Emmons and Crumpler (2000) posed the question: “What form does the expression of gratitude take in instances where it is truly impossible to repay one’s debt?” (p. 67), and suggested that the recipients of donated organs may be just such a population. The magnitude of the ‘gift’ transplant recipients receive (i.e., one that is “impossible to repay”) is foregrounded in the gift-of-life metaphor, which is ubiquitously applied in the context of transplantation (Fox & Swazey, 2002; Shaw, 2010, 2012; Shaw et al., 2012; Siminoff & Chillag, 1999; Sothern & Dickinson, 2011). Several reasons have been tendered to account for its common usage: it alerts the public to the good that transpires from transplantation, and the need to increase rates of transplantation; it underscores the principle of voluntary altruism, upon which the donation system is premised; and it engages recipients in a ‘construction of care’ (e.g., encourages gratitude in recipients), which means they will be more likely to take care of their health post-transplant (Sothern & Dickinson, 2011).

If, as Frank (1995) suggests, “metaphor establishes a storyline” (p. 57) then the storyline established by the gift-of-life metaphor is, in no small part, one of gratitude. The life of a transplant recipient is perceived as ‘a gift’, and he/she is expected to live in
permanent recognition of this. A gift entails gratitude, and his/her life (post-transplant) must be lived in gratitude (as recognition of, and for, the gift received in transplantation). There are a number of implications stemming from the widespread use of gift discourse in the transplantation milieu and these have been covered, in depth, in the preceding chapter. Suffice to say, here, that gratitude is normatively expected in the context of organ transfer.

Gratitude is a recurring theme in transplantation research: although, for the most part, it is indirectly targeted. It can be found, for example, in research concerned with gift exchange (Gill & Lowes, 2008), gift-of-life (Shaw, 2012), and quality of life post-transplant (Dudley, Chaplin, Clifford & Mutimer, 2007). Given the normative expectation of gratitude, and the general paucity of gratitude research in this context, one of the primary objectives of this thesis was the exploration of gratitude as it pertains to transplantation, particularly with respect to gift-of-life discourse.

I begin this chapter with a general outline of the current gratitude literature. This is followed by a more in-depth review of the literature, beginning with an overview of advances in the positive psychology movement, as it is from within this movement that the current interest in gratitude has evolved. An in-depth appraisal of the gratitude literature (including an outline of the complexities of gratitude as a construct) follows, and I conclude with a consideration of applied gratitude research.

### 3.1 Gratitude, and the origins of contemporary gratitude research

Contemporary French philosopher Andre Comte-Sponville’s (2002) depiction of gratitude as “the most pleasant of virtues and the most virtuous of pleasures” underscores the sense of old-fashioned quaintness often associated with it (p. 132). Contemplation of this
sentiment might well generate images of Victorian parlours and well-bred young ladies endeavouring to write the perfect thank-you letter. When contemplating life in twenty-first century society, though, one may wonder if gratitude has gone the way of many Victorian niceties. Indeed, Solomon (2006) argued that gratitude has become a ‘hypocognized’ emotion in Western cultures, seldom the focus of thought or conversation. He reported that conversations in his own culture (i.e., North America) were more likely to be dominated by outrage, envy, or resentment, and attributed this to a growing sense of entitlement within some subcultures.

While gratitude has been the source of much philosophical deliberation throughout history, it has tended to elude the searchlight of psychological enquiry (Emmons, 2004). This issue has been addressed in more recent times, with a burgeoning interest in this construct emerging from within the realms of positive psychology (McCullough et al., 2001). A PsychInfo search of peer-reviewed articles, with gratitude as an ‘Identifier (key word)’, produced 22 results in the period January 1975 to December 1999, but over twenty times that number (i.e., 469 results) in the period January 2000 to November 2014. While this does not come close to matching the attention given to the negative states of anxiety (i.e., 23,790 results in the first period, and 64,052 in the second) or depression (i.e., 36,406 results in the first period, and 110,100 in the second), it demonstrates curiosity regarding gratitude and attempts to redress the paucity of gratitude research.

We might traditionally think of gratitude as being for the benefactor (i.e., gratitude is good because the benefactor deserves it, not because it does good things for the person who is grateful). However, most psychological research has focused on the benefits of
gratitude for the one feeling grateful, and has thus identified some of the benefits that might ensue from its practice. Gratitude has been positively associated with: better sleep (Wood, Joseph, Lloyd, & Atkins, 2008); proactive coping (Vernon, Dillon, & Steiner, 2009; Wood, Joseph, & Linley, 2007); protection from stress and depression (Wood, Maltby, Gillett, Linley, & Joseph, 2008); high-quality relationships (Algoe, 2012; Algoe & Stanton, 2012); reductions in materialistic strivings (Polak & McCullough, 2006); enhanced well-being (Emmons & McCullough, 2003; Lambert, Graham, Fincham, & Stillman, 2009; Rash, Matsuba, & Prkachin, 2011); increased life satisfaction (Lyubomirsky, Sheldon, & Schkade, 2005; Toepfer, Cichy, & Peters, 2012); and increased longevity (Danner, Snowdon, & Friesen, 2001). The wide array of benefits associated with gratitude has lent credence to the stance of Wood, Maltby, Gillett, Linley, and Joseph (2008) who postulated that gratitude is possibly “the quintessential positive psychological trait” (p. 854).

Gratitude may also represent an antidote to envy. McCullough, Emmons and Tsang (2002) found that gratitude and envy were inversely related, and argued that these two emotions are premised on disparate cognitions and affective states. The grateful accentuate the positive in their focus on the contributions that others have made to their lives and their savouring of positive experiences, while the envious tend to compare their lot with that of others and a negative state ensues (fuelled by longing for what others have, resentment and frustration). These differences suggest an incompatibility, and the two states are unlikely to be experienced simultaneously. It is thus not inconceivable to suggest that the concerted practice of gratitude may go some way toward countering the tendency toward outrage, envy and resentment outlined by Solomon (2006).
3.1.1. Positive psychology and the pursuit of happiness

The positive psychology movement investigates factors (i.e., positive emotions, positive character traits, and positive institutions) that enhance happiness and contribute to human flourishing (Seligman, Steen, Park, & Peterson, 2005). Research has indicated there are practices that can enhance happiness, or subjective well-being as it is commonly referred to in the psychological literature, and gratitude is considered to be of importance in this regard (Emmons & McCullough, 2003; Rash, Matsuba, & Prkachin, 2011; Watkins, Grimm, & Kolt, 2004).

The contemporary interest in the pursuit of happiness is revealed in a search of the self-help section in Amazon.com, where ‘happiness’ entered as the search criterion, returned 18,313 titles. Those in hot pursuit of happiness can trawl their way through tomes such as Happiness: A Guide to Developing Life’s Most Important Skill, The Ten Laws of Happiness, Happiness in Five Minutes a Day, Happiness Now!, Happiness is a Serious Problem, Happiness is an Inside Job, and Money Can Buy Happiness. It was interesting to note that happiness is not reserved for any particular sector of society: the young can be happy (e.g., Have You Filled A Bucket Today: A Guide to Daily Happiness for Kids; Happiness is a Choice for Teens); the not-so-young can be happy (e.g., The Method of Enjoying Complete Happiness in Old Age); women can be happy (e.g., Field Guide to Happiness for Women); men can be happy (e.g., What Would Mickey Say: Coaching Men to Health and Happiness); and yes, dummies too can be happy (e.g., Happiness for Dummies); as can complete idiots (e.g., The Complete Idiot’s Guide to the Psychology of Happiness). The sheer volume of material available on this topic may lead one to believe that the attainment of happiness is the contemporary virtue and represents
the Holy Grail of life in many Western societies. This raises the question asked by Lyubomirsky, Sheldon and Schkade (2005): “Is the pursuit of happiness merely a bourgeois concern, a symptom of Western comfort and self-centredness, a factor that has no real impact on psychological adjustment and adaptation?” (p. 111). Drawing on extensive empirical research, Lyubomirsky and her colleagues build a solid case in defence of happiness and its pivotal role within the development of positive mental health.

The positive psychology movement emerged at the turn of the new millennium, as its founding fathers, Martin Seligman and Mihalyi Csikszentmihalyi, argued for a wider focus within mainstream psychology: that is, a shift from an outlook concentrated on pathology (i.e., damage control and damage repair) towards a more encompassing view in which the factors that contribute to human flourishing are just as vigorously examined (Seligman & Csikszentmihalyi, 2000). While the shift in focus would appear, at least on the surface, to be beyond reproach, this ‘new’ psychology has not escaped criticism. Barbara Held, for example, admonished the founders of the positive psychology movement for their separatist, polarising rhetoric (Held, 2002, 2004). She denounced the ‘tyranny of the positive attitude’, which she described as a call for positivity under any and all circumstances. Furthermore, she drew attention to the shadow side of positive psychology, censuring positive psychologists for their negativity about negativity. In their report on the progress of positive psychology, Seligman et al. (2005) countered some of Held’s claims, stating emphatically that the study of that which causes us to flourish serves to augment what is known about human suffering, not usurp it. These researchers
reiterated the view that a balanced investigation of human experience, in all of its guises, is crucial to the ‘complete practice’ of psychology.

The happiness ‘set point’ has been of considerable interest to those investigating subjective well-being (Diener, Suh, Lucas, & Smith, 1999; Krause & Sternberg, 1997; Lucas, 2007; Lucas, Clark, Georgellis, & Diener, 2003, 2004; Lykken & Tellegen, 1996; Lyubomirsky et al., 2005). It has been defined as a genetically determined set point of affectivity to which individuals consistently return, regardless of life’s vicissitudes (Peterson, Park, & Seligman, 2005). In their seminal investigation of hedonic adaptation, Brickman, Coates, and Janoff-Bulman (1978) found that regardless of what life sets in our path (that is, the low-lows or the high-highs), we adapt and return to our ‘happiness set point’. Lyubomirsky et al. (2005) suggest some practices might influence this set point and, in so doing, facilitate alterations in well-being. Gratitude is one of these factors.

### 3.2 Gratitude theories

Traditionally, negative emotions have captured the interest and attention of theorists, while positive emotions have remained outside the laboratory door, so to speak, largely ignored and, consequently, unexplained. Fredrickson (1998) is among the forerunners of those who have worked towards accounting for positive emotions in greater depth, and she proffered the broaden-and-build model of positive emotions to explain the unique effects of positive emotions. She argued that positive emotions have been marginalised, with many emotion theorists attempting to mould positive emotions to ‘fit’ the model of more prototypic (negative) emotions such as anger and fear. The underlying premise of many current theories of emotion is that emotions are defined largely by the specific action tendencies (i.e., urges to act in particular ways) with which they are associated.
(Frijda, Kuipers, & Schure, 1989; Oatley & Jenkins, 1996). Anger, for example, is associated with the urge to attack, and fear with the urge to flee. Fredrickson claimed that while specific action tendencies may adequately explain the form and function of negative emotions, they do not serve positive emotions well.

From an evolutionary perspective, the narrowed thought-action repertoire associated with negative emotions is highly adaptive: in life-threatening situations, rapid, decisive action may be essential to ensure survival. Fredrickson (1998) argued that positive emotions are experienced in a different domain (i.e., more likely to occur when the individual feels secure and satiated), and therefore more readily defined by an entirely different thought-action repertoire. From the broaden-and-build perspective, positive emotions are seen to broaden attention and thinking, enabling access to a more extensive range of percepts or ideas. Broadened mindsets, in turn, build enduring personal resources (e.g., cognitive, psychological, social and/or physical) that accumulate over time and increase well-being (Fredrickson, Cohn, Coffey, Pek, & Finkel, 2008).

The broaden-and-build model is not a one-size-fits-all approach to positive emotions. Positive emotions are seen to broaden-and-build in diverse ways: joy fosters the urge to play and be creative; interest fosters the urge to explore and learn; and pride following a personal achievement fosters the urge to envision future achievements (Fredrickson, 1998). Fredrickson (2004) posits that gratitude fosters the urge to behave prosocially. The grateful individual does not engage in a narrow tit-for-tat approach. He/she thinks creatively about ways in which the welfare of others (including the original benefactor) may be enhanced and, over time, this leads to the strengthening of social bonds and friendships. These bonds and friendships represent social resources that may
be the font of considerable support in times of hardship. The prosocial ‘fallout’ from gratitude reverberates throughout the wider community, linking individuals to society, and building the community’s social resources also.

Much of the empirical research concerning gratitude is based on a social exchange (i.e., interpersonal accounting) model. That is, the extent to which gratitude is experienced depends on the recipient’s appraisal of: the value of a received benefit to him/her; the cost of the benefit to the benefactor; and repayment of the benefit, from recipient to the benefactor or third party. Algoe, Haidt, and Gable (2008) argued, though, that those concerned with gratitude need to move ‘beyond reciprocity’ when attempting to explain how gratitude functions in social life, as gratitude represents more than merely repaying a benefit. They investigated relational appraisals across what they deemed to be ‘a naturally occurring gratitude intervention’ among sorority sisters at a university campus (where new members to a sorority chapter, Little Sisters, receive gifts from and attend events planned by longer term members, Big Sisters, across four days at the beginning of their first semester). They found that Little Sisters’ appraisals of their Big Sisters’ responsiveness (i.e., thoughtfulness in providing a particular benefit) positively predicted the Little Sisters’ feelings of gratitude. Also, perceived responsiveness predicted gratitude more consistently than the value of the benefit (i.e., how much it was liked), the real or perceived cost of the benefit (to the benefactor - in terms of both effort and dollar-value) and the extent to which the benefit was a ‘surprise’.

The ‘find-remind-and bind’ model of gratitude has been proffered to account for gratitude’s capacity to facilitate a relationship-building interchange between a recipient and his/her benefactor (Algoe et al., 2008). In this model, gratitude functions as “a
detection-and-response system to help find, remind, and bind ourselves to attentive others” (p. 429). Gratitude, thus, plays an important role in the formation and maintenance of important relationships: those we can draw on in difficult times, and that enable us to flourish in good times. Algoe et al.’s (2008) find-remind-and-bind model expands on Fredrickson’s (2004) broaden-and-build theory of gratitude in its account of how gratitude, as a prosocial emotion, fosters and strengthens relationships. This particularly holds for the types of relationships that might later represent important social resources.

According to the social functional (i.e., relational) account of gratitude, gratitude is triggered for the recipient of a benefit, in part, because of the salience of the benefit as a ‘responsive action’ from the benefactor (Algoe, 2012). That is, it indicates that the benefactor understands, approves or cares about the recipient (Reis, Clark, & Holmes, 2004). The experience of gratitude influences (or, as Algoe stated, ‘updates’) the recipient’s view of the benefactor: the grateful recipient, thus, ‘finds’ new relationship partners or is ‘reminded’ of current high-quality partners. Gratitude facilitates the formation and/or maintenance of relationships, as it ‘binds’ the relationship partners (i.e., recipient and benefactor) more closely together. The understanding of a received benefit as a ‘responsive action’ is central to the find-remind-and bind account of gratitude’s role in relationship formation and maintenance (Aloe, 2012). The sense of being understood, approved of and/or cared for is a key component of relational intimacy in close, communal, reciprocally altruistic relationships where benefits are provided on the basis of need rather than on an expectation of repayment (Reis et al, 2004).
Research on the find-remind-and-bind model of gratitude was furthered in a study conducted by Algoe, Fredrickson and Gable (2013). In this study, the benefactor (i.e., the target of gratitude) was the focus of attention. Algoe et al. questioned whether the target’s understanding of the expresser’s responsiveness might influence relationship quality. Findings showed that benefactors’ perceived responsiveness in expressed gratitude positively predicted their relationship satisfaction over a period of (at least) six months. Algoe et al. posited that their study demonstrated the relational benefits of expressed gratitude, and this confirmed their view that “gratitude fuels mutual cyclical growth” for those in close relationships (p. 605). The work of Gordon, Arnette, and Smith (2011) also demonstrated the relational benefits of gratitude. In this instance, though, the relationships investigated were long-term relationships (mean relationship length was 20.7 years). They found that felt (i.e., inward) and expressed (i.e., outward) gratitude positively predicted the individual’s own relationship satisfaction. Inward gratitude also positively predicted the marital happiness of the individual’s spouse, but expressions of gratitude did not. Gordon et al. (2011) argued that gratitude is an important construct in terms of its potential to contribute to the achievement of deeply satisfying and flourishing relationships.

### 3.3 Gratitude: A complex construct

There is no simple answer to the question of what constitutes gratitude, as it is a complex phenomenon, and any attempt to fully capture its essence within a one-or-two sentence definition is doomed to failure. Nevertheless, I will attempt a brief description below, and then outline the concept of gratitude more fully thereafter.
In a broad sense gratitude can be viewed as a human strength that serves to lubricate the cogs and wheels of social interaction, promoting both personal and interpersonal well-being (Emmons & Crumpler, 2000). Gratitude occurs in response to benefits that have been intentionally given, are perceived as being of value, and are given at some cost/effort on the part of the benefactor (McCullough et al., 2001; McCullough & Tsang, 2004). Gratitude is understood to be a personality trait as well as a state (McCullough et al., 2002). As outlined previously, it can be cultivated as a practice to enhance well-being (Emmons & McCullough, 2003; Rash et al., 2011; Watkins et al., 2004), and is also understood to play an important role in post-traumatic growth (Linley & Joseph, 2004; Ruini & Vescovelli, 2013; Wood, Froh, & Geraghty, 2010).

3.3.1 Gratitude as a personality trait

With respect to gratitude as a personality trait, McCullough et al. (2002) defined it “as a generalized tendency to recognize and respond with grateful emotion to the roles of other people’s benevolence in the positive experiences and outcomes that one obtains” (p. 112). As an outcome of their research, McCullough and his colleagues created a profile of the grateful person. Compared to those who are less so, the grateful person is likely to experience more positive emotion (i.e., life satisfaction, vitality, subjective happiness, optimism and hope), and less depression, anxiety and envy. According to both self-report and informant-report measures, the grateful person is also likely to be more prosocially disposed, displaying greater levels of empathic concern and perspective taking, and performing more prosocial behaviours (e.g., providing favours, volunteering to help others, being generous with time and resources). Finally, the grateful person is likely to have a more religious and/or spiritual orientation toward life.
The characteristic schemas of the dispositionally grateful influence their understanding of help-giving situations (Wood, Maltby, Stewart, & Joseph, 2008). Wood et al. (2008) investigated a life orientation view of gratitude, and found that the dispositionally grateful perceived help as being more costly, valuable, and altruistic. Findings from this research confirmed the existence of a latent grateful personality (i.e., higher order gratitude construct), with eight lower order facets. These facets are: individual differences in the experience of grateful affect; Interpersonal (i.e., appreciation of other people); “Have” focus (i.e., a sense of abundance); Awe (i.e., feelings of wonder when encountering beauty); Ritual (i.e., regular expression of gratitude behaviours); Present Moment (i.e., a focus on the positive in the present moment); Loss/adversity (i.e., appreciation stemming from the understanding that nothing in life is permanent); and Self/social comparison (i.e., positive social comparisons stemming from an understanding that life could be worse).

The disposition towards gratitude mediates the link between daily emotional experience and grateful mood (McCullough, Tsang, & Emmons, 2004). Based on a model proposed by Rosenberg (1998), moods are considered to occupy intermediate terrain in the hierarchy of affective phenomena. Moods fall midway between traits (i.e., placed at the top of the ladder as they represent the most stable phenomena, which set the stage for the enactment of specific emotional states) and emotions (i.e., discrete episodes; acute and intense; placed at the bottom of the ladder). In their investigation of trait gratitude, McCullough et al., (2004) found that the number of daily gratitude-relevant experiences and the intensity of emotional reactions to these experiences led to variations in grateful mood. The experience of many gratitude-inducing episodes, accompanied by a high level
of grateful emotion per episode, aggregated to cast a grateful ‘glow’ over daily mood. However, the disposition toward gratitude interceded along the pathway from grateful emotion to grateful mood. McCullough et al. (2004) argued that grateful mood is strongly driven by personality. The dispositionally grateful are less susceptible to the vagaries of gratitude-relevant aspects of their daily lives. They are likely to experience the ‘glow’ of grateful mood regardless of fluctuations in gratitude-relevant situations and the emotional reactions induced by them.

A social-cognitive model of gratitude (see Figure 1 below) was proposed to account for the relationship between trait and state gratitude (Wood, Maltby, Stewart, Linley, & Joseph, 2008). The links between the individual components of this model are detailed as follows: a) a benefit appraisal is formed after a person receives a benefit of some kind. This appraisal is premised on a cluster of attributions that the person makes regarding the benefit; b) benefit appraisals generate the experience of state gratitude: c) the dispositionally grateful are characterised by an interpretive bias that leads to the creation of more positive benefit appraisals than their less grateful counterparts; and d) the higher rate of positive benefit appraisals mediates the relationship between trait and state levels of gratitude.

Figure 1. A social-cognitive model of trait and state levels of gratitude. Adapted from “A social-cognitive model of trait and state levels of gratitude” by A. M. Wood, J. Maltby, N. Stewart, P. A. Linley and S. Joseph, 2008, Emotion, 8, p. 282.
Across the three studies of the Wood et al. (2008) research, benefit appraisals were found to be the generative mechanism accounting for the tendency of the dispositionally grateful to experience more gratitude after they have received help. The relative importance of the individual variables in the model was also ascertained: the highest proportion of variance was attributed to situational factors and benefit appraisals; and a smaller, but important, proportion was ascribed to trait gratitude, which was seen to wield its influence by casting a positive attributional bias over the appraisal of a situation.

### 3.3.2 The moral imperative of gratitude

It is important to address the moral imperative of gratitude when attempting to understand the construct in its totality (Emmons & McCullough, 2003). McCullough et al. (2001) referred to gratitude as a ‘moral affect’. Not that the emotion itself was believed to be moral: gratitude was considered to be moral in the sense that it represents both cause and consequence of moral behaviour (i.e., that concerned with the welfare of others).

McCullough et al. posited a theoretical framework for the contemplation of gratitude as ‘moral affect’, and within this framework gratitude serves three prosocial or moral functions: ‘moral barometer’, ‘moral motive’, and ‘moral reinforcer’.

#### 3.3.2.1 Gratitude as a ‘moral barometer’

Gratitude as a ‘moral barometer’ operates at an informational level: alerting the individual to particular alterations in his/her interpersonal milieu that are likely to increase well-being (McCullough et al., 2001). As a moral barometer, gratitude relies on social-cognitive input. Individuals are considered most likely to feel grateful when four conditions are met: a) they receive a benefit that they value; b) the benefit involves cost
(e.g., effort) on the part of the benefactor; c) the benefit was given with benevolent intentions (i.e. it was not incidental); and d) the benefit was given gratuitously (i.e., it was not dependent on role-based obligations).

3.3.2.2 Gratitude as a ‘moral motive’

Gratitude as a ‘moral motive’ is associated with a specific action tendency, and that is to behave prosocially (Fredrickson, 2004). The grateful person is likely to reciprocate for the benefits they have received by contributing to the benefactor’s welfare (or that of a third party) in the future. Bartlett and DeSteno (2006) found strong evidence for gratitude’s causal efficacy in the promotion of prosocial behaviour. Across three studies, participant-gratitude, rather than general positive state or prosocial norms, was shown to promote engagement in helping behaviours (to both benefactors and strangers). Tsang (2006) utilised a laboratory gratitude-induction technique to investigate prosocial responses to gratitude. In this study, participants received varying amounts of money from a ‘partner’ in a resource distribution task. Tsang found that participants who experienced gratitude (i.e., those in the Favour condition who believed their partner had given them a relatively large amount of money, while keeping only a small amount for herself) reported being motivated by their gratitude, and acted more prosocially (i.e., they gave their partner more money) than those who had received the same amount of money in the Chance condition. Bartlett, Condon, Cruz, Baumann, and DeSteno (2012) also investigated the prosocial tendencies associated with gratitude in their study of the influence that gratitude might have on relationships. They found that recipients’ gratitude motivated them to spend more time with their benefactors and engage in more relationship-strengthening behaviours (e.g., social inclusion), even when these behaviours were costly.
3.3.2.3 Gratitude as a ‘moral reinforcer’

The ‘moral reinforcer’ function of gratitude is enacted when the grateful person expresses his/her appreciation. The expression of gratitude is likely to reinforce the benefactor for his/her benevolence and encourage the benefactor to continue behaving in a similar manner in the future (McCullough et al., 2001). In a study of helping behaviour, Deutsch and Lamberti (1986) reported that social approval (e.g., praise or gratitude) facilitates further prosocial behaviour. They found that when appreciation was expressed to participants who had engaged in helping behaviour, they were more likely than those who had not been thanked to help a confederate in the study at a later time. The reinforcement of benefactor behaviour was also the source of interest in a study of prosocial behaviour, conducted by Grant and Dutton (2012). They found that reflection on being a benefactor was a more powerful driver of prosocial behaviour than reflection on being a beneficiary of help. Participants in the benefactor condition were more likely to donate their time and money to others than those in the beneficiary condition. Grant and Dutton argued that, in terms of enhanced prosocial behaviour, it might be better to give than to receive.

The moral reinforcer function of gratitude can also be seen at work in HIV/AIDS care. Bennett, Ross and Sunderland (1996) highlighted the considerable stress involved in providing care for those with HIV/AIDS, and the importance of rewards in this context. In their study, the presence of stress and lack of reward (e.g., gratitude from clients, recognition and support from management) were independently related to burnout frequency. Bennett et al. posited that rewards, such as gratitude, acted as a buffer against stress and burnout for volunteers, enabling them to continue ‘giving’ (i.e., volunteering) in this situation.
3.4 Gratitude and indebtedness

Gratitude and indebtedness are both potential responses to the receipt of a gift. Komter (2004) stated that “gratitude is not always the positive and unproblematic phenomenon we would like it to be, but may be complicated by issues of power and dependence” (p. 206). She elaborated on the manner in which power or dependence may cause asymmetry within a relationship; leading to one party feeling, or being, obliged to give more than the other. Komter treats gratitude and indebtedness as if they are the same phenomenon. However, research indicates that the two are discrete emotional states; each associated with distinct action tendencies (Matthews & Green, 2010; Tsang, 2006; Watkins et al., 2006).

The norm of reciprocity is the source of indebtedness (Tsang, 2006). That is, when the indebted individual receives a benefit, he/she feels obligated to return the favour. Although the grateful individual is also influenced by this norm, he/she is not held to ransom by a tit-for-tat mentality. Tsang (2006) examined the influence of helper-intention (i.e., benevolent or selfish) on grateful and indebted reactions to a favour, and found a significant increase in grateful response if the intentions of the helper were perceived to be benevolent. Levels of indebtedness, though, were not influenced by helper-intention. Tsang surmised that the positive valence of the grateful response was susceptible to the influence of helper-intention, whereas the indebted response, operating as a function of the norm of reciprocity, was generally impervious to helper-intention.

In a related vein, Watkins et al. (2006) found that an indebted response increased with increasing expectations of return from the benefactor. In this research gratitude was seen to be a positive affective experience, associated with broad prosocial (i.e., approach)
action tendencies and the inhibition of antisocial tendencies. Indebtedness, in contrast, was seen to be a mixed, but negatively biased, emotional experience. It was aligned with an increased probability of antisocial tendencies (i.e., rejection and avoidance), and although there were some prosocial tendencies associated with indebtedness, they tended to be much weaker than was the case with gratitude.

Self-focused attention might represent one of the key cognitive mechanisms underlying indebtedness, and a means of differentiating indebtedness from gratitude. Matthews and Green (2010) found that self-awareness (i.e., social anxiety and public self-consciousness) was positively associated with indebtedness, and social anxiety was negatively associated with gratitude. They concluded that when an individual is self-focused, he/she is likely to recall a favour with indebtedness rather than gratitude. They speculated that this might occur via three routes. In the first of these, self-focus might reduce empathic accuracy such that the highly self-focused individual is unable to accurately determine the motivation behind a gift/benefit (i.e., altruistic vs expectation of later repayment) and defaults to the norm of reciprocity. In the second, self-focus directs attention toward issues of equity, and the highly self-focused individual is oriented toward the norm of reciprocity in a bid to restore balance. In the final potential route, self-focus leads to assessments of self and standards, and negative affect ensues when the highly self-focused individual perceives a discrepancy between the magnitude of the received benefit and his/her attempts at thankfulness/repayment. That is, when he/she perceives a failure to produce enough ‘tit’ for ‘tat’.
3.5 Gratitude practices and well-being

The benefits arising from a simple practice of gratitude were investigated in Emmons and McCullough’s (2003) renowned ‘Counting Blessings’ research. They conducted three studies, with samples that included university students and individuals with neuromuscular disease, over periods ranging from two to ten weeks. Participants in the gratitude condition of each of the studies were asked to think about their lives and list up to five things for which they were grateful. Those in the gratitude manipulations reported a number of positive effects when compared with those in the ‘hassles’ or ‘neutral’ conditions. These included: feeling better about life as a whole; increased positive affect; higher optimism; fewer symptoms of physical illness; increased time spent exercising; increased satisfaction with life; more, and better quality, sleep; and increased sense of connectedness to others. Emmons and McCullough posited that consciously contemplating one’s blessings can lead to increases in subjective well-being.

In more recent research, Rash et al. (2011) also investigated the capacity of a gratitude practice to enhance well-being. Participants who engaged in a reflection process (i.e., thought about items/people/events for which they were particularly grateful) reported higher life satisfaction and self-esteem than those who recalled memorable events. They also experienced higher cardiac coherence, which has been associated with a number of positive outcomes including general well-being, reduced stress, and increases in the body’s regenerative processes (McCraty & Childre, 2010). Rash and his colleagues suggested that ‘simply’ thinking about the things for which one is grateful is sufficient to produce positive effects on well-being.
Like participants in the Emmons and McCullough (2003) study, outlined previously, participants in Watkins et al.’s (2004) research were also asked to ‘count their blessings’. Watkins and his colleagues postulated that when asked to recall past life events, some individuals (i.e., those who are more grateful) are likely to reflect back on pleasant memories; that is, they have a positive memory bias. The emotional impact of memories was also investigated in this study, and the outcomes were particularly interesting. Both positive and negative memories became less intense over time: negative memories tended to improve (i.e., lose some of their sting) and positive memories tended to decrease in terms of emotional impact (i.e., lose some of their joy). However, the negative memories showed more change over time than did the positive memories. That is, for grateful individuals, negative memories lost more of their sting than positive memories lost of their joy. Grateful individuals also showed more emotional recovery after negative life events than did the less grateful.

Counting one’s blessings may counteract hedonic adaptation, one of the major impediments to an enduring sense of well-being (Watkins et al., 2004). Hedonic adaptation accounts for the tendency to return to baseline levels of happiness after alterations, both minor and major, in life circumstances (Lucas, 2007). The Law of Habituation is one of Frijda’s (1988) laws of emotion, and states that “Continued pleasures wear off; continued hardships lose their poignancy” (p. 353). Frijda conceived of this law to be both saddening (i.e., love gradually loses its magic) and consoling (i.e., the pain of loss abates over time). On a more positive note, he stated that the outcome of this law is not unavoidable: “Adaptation to satisfaction can be counteracted by constantly being aware of how fortunate one’s condition is and how it could have been otherwise, or
actually was otherwise before – by rekindling impact through recollection and imagination” (p. 354). It appears that an enduring sense of well-being is, at least theoretically, possible. However, it does not come easily, requiring careful cultivation and nurturance. Gratitude, as a deeply appreciative attitude towards life, has been posited as one of the central ways in which well-being can be perpetuated and sustained (Adler & Fagley, 2005; Polak & McCullough, 2006; Watkins et al., 2004).

3.6 **Gratitude as a coping mechanism**

“One of the most salient features of grateful people is that they seem to very good at coping with obstacles and difficult events” (Watkins, 2014, p. 170). Research has indicated that gratitude does indeed function as a coping mechanism and thus has a role in resilience, adaptive coping and recovery from traumatic events (Fredrickson, Tugade, Waugh, & Larkin, 2003; Teigen, & Jensen, 2011).

Gratitude has been shown to enhance coping via a positive memory bias (Watkins et al., 2004). One of the major implications arising from Watkins et al.’s (2004) research is the manner in which the recollection of events might enhance coping and influence subjective well-being. Positive recollections increased satisfaction with life ratings (see also Strack, Schwarz & Gschneidinger, 1985), and gratitude assisted in the processing of unpleasant emotional memories (see also Rachman, 1980). Taken together, these findings indicate that grateful individuals engage in positive reframing. This has the dual effect of reducing the negativity of unpleasant memories, and orienting these individuals toward redemptive sequences in their life stories (where positive consequences are drawn from negative life events). McAdams, Reynolds, Lewis, Patten and Bowman (2001) found that
redemptive sequences (i.e., those in which bad things turn good) predicted life satisfaction more readily than did the overall positivity of life stories.

Grateful processing of unpleasant memories might help individuals ‘take care of business’, in terms of adaptive coping (Watkins, Cruz, Holben, & Kolts, 2008). In an investigation of their theory that gratitude functions by way of positive reappraisal, Watkins et al. (2008) found that participants who wrote about the positive consequences of an unpleasant experience, which they are now grateful for, demonstrated adaptive coping. That is, they showed more closure, as well as less unpleasant emotional impact and memory intrusiveness than did those who wrote about any/all emotions and thoughts in relation to an unpleasant experience or those who wrote about their plans for the next day. Watkins and his colleagues suggested two ways in which grateful processing might influence coping. In the first of these, grateful processing of an open unpleasant memory changes the memory (i.e., positive outcomes of the troubling/difficult experience are brought to the fore). This ‘new’ memory of the experience fits more meaningfully within the individual’s ‘good’ life story (see McAdams et al., 2001), resulting in closure and reduced memory intrusiveness. In the second, engaging in benefit-finding (i.e., finding ‘good’ from within ‘the bad’) enhances gratitude, which has positive effects on well-being.

Gratitude may also aid coping and have clinical application with respect to the treatment of stress and depression (Wood, Maltby, Gillett, Linley, & Joseph, 2008). Wood et al. (2008) found that trait gratitude led to increased levels of perceived social support, and lower levels of stress and depression during a period of transition (participants were university students in their first semester). Vernon, Dillon, and Steiner
(2009) studied the relationship between gratitude and proactive coping in a sample of female undergraduate students with post-traumatic stress disorder (PTSD). Proactive coping is future-oriented, and was described as a means of building resources (e.g., cognitions, actions and skills) such that the attainment of future goals and personal growth is facilitated. It differs from reactive coping, which directs resources toward the past and events that have already taken place. Retrospective reports revealed that higher levels of gratitude were associated with fewer PTSD symptoms and reduced symptom-severity post-trauma. The emotional benefits of gratitude were long lasting, evident months, and even years, after the traumatic event had taken place. This study indicates that gratitude is a protective factor for women, contributing to proactive coping and post-traumatic growth. Vernon et al. theorised that gratitude-enhancing cognitions (e.g., benefit-finding) are incompatible with those (e.g., self-blame) that lead to conditions such as PTSD.

In further research examining gratitude and PTSD, Kashdan, Uswatte, and Julian (2006) found that trait gratitude was significantly lower in Vietnam war veterans who experienced PTSD than in those who did not. Kashan et al. stressed their alliance with the view “that wellness is more than the absence of distress” (p. 180). Based on this understanding of wellness, they included measures of both hedonic (i.e., the experience of physical and emotional pleasures generally called happiness) and eudaimonic well-being (i.e., the experience of enriching activities that lead to personal growth and flourishing) in their study. Gratitude was lower in veterans who experienced PTSD, and trait gratitude predicted increased hedonic and eudemonic well-being in those with PTSD, irrespective
of symptomatology. These findings indicate that further exploration of gratitude in the context of trauma survival is warranted.

In their review of positive change following trauma (which they call ‘adversarial growth’), Linley and Joseph (2004) argued that studying only the negative consequences of trauma and adversity leads to a partial, and biased, understanding of trauma reactions. If trauma recovery is to be comprehensively understood and attended to, the potential for positive change (i.e., post-traumatic growth) must also be taken into account. Based on the correlational and longitudinal evidence on which their review was based, they found that positive reinterpretation and acceptance coping are the factors most often linked with greater adversarial growth.

3.7 Gratitude and post-traumatic growth

Research indicates that gratitude might play a critical role in post-traumatic growth (Linley & Joseph, 2004; Ruini & Vescovelli, 2013; Wood et al., 2010). Ruini and Vescovelli (2013) investigated the role of gratitude, as it relates to post-traumatic growth, psychological well-being and distress, in a sample of women with breast cancer. They found that gratitude was positively associated with all dimensions of post-traumatic growth. That is: positive relations; new possibilities; personal strengths; spiritual changes; and appreciation of life. Gratitude was also positively associated with the hedonic well-being dimensions of contentment and relaxation, and negatively associated with the dimensions of anxiety, depression and hostility. Ruini and Vescovelli argued that gratitude functions as a buffer (with respect to negative affect and psychological symptoms) in oncology patients.
In research on trauma, findings suggest that recovery is influenced by the extent to which the traumatised individual can find some ‘good in the bad’ (e.g., Frazier, Conlon, & Glaser, 2001; Vernon, Dillon, & Steiner, 2009). Benefit-finding (i.e., cognitive reappraisal) is a form of grateful processing that can enhance coping, with positive effects on well-being (Watkins et al., 2008). The types of ‘benefits’ typically reported following trauma (e.g., greater appreciation of others and of life, recognition of the finiteness of life; c.f. Linley & Joseph, 2004) are exactly those that have been associated with gratitude (Wood, Maltby, Stewart, & Joseph, 2008). As Wood et al. (2010) highlighted, though, the evidence linking gratitude with post-traumatic growth is, for the most part, indirect.

Gratitude interventions (e.g., grateful contemplation; listing things for which one is grateful; gratitude journals; writing letters of gratitude) have shown to be efficacious, in terms of enhanced well-being, over relatively short periods of time (Emmons & McCullough, 2003; Rash et al., 2011; Seligman et al., 2005). Greater understanding of gratitude, particularly gratitude in chronically stressed populations, has the potential to lead to greater understanding of the type of interventions that might lead to enhanced well-being and the role of gratitude in post-traumatic growth.

### 3.7 Conclusion

Gratitude has been conceptualised as a positive emotion typically experienced in response to a benefit (i.e., tangible or intangible) that has resulted from the costly, intentional and voluntary action of another person (McCullough et al., 2001). McCullough et al. (2001) postulated that gratitude functions as a moral affect. Functioning as a moral barometer/detector, it alerts people to the ways in which they have benefitted as a result of the actions of others. Gratitude promotes prosocial behaviour, on the part of recipients,
who attempt to reciprocate for the benefit/s received. Gratitude also reinforces the prosocial behaviour of the benefactor, thereby increasing the likelihood that the benefactor will engage in such behaviour in the future.

Transplantation is founded on gift-of-life discourse; that is, the idea that donated organs represent the gift of life itself, and are thus ‘gifts’ of immeasurable value (Fox & Swazey, 2002). Gift-of-life discourse foregrounds gratitude as the appropriate emotional response in the context of organ transfer, and gratitude is normatively expected in this context. However, from the purview of transplantation there is a tendency to perceive gratitude as a static one-dimensional construct, and this glosses over the complexity of gratitude. There is a paucity of research regarding the experience of gratitude in chronically stressed populations, and particularly in a population where the moral imperative for gratitude is so firmly rooted. There is also little known of the psychological repercussions for those who do not feel grateful in a context where society holds that they should be unequivocally grateful. The sphere of transplantation thus provides fertile ground for the exploration of gratitude.
CHAPTER FOUR

Methodology and method: Phenomenology, and interpretative phenomenological analysis (IPA)

A story is not like a road to follow … it's more like a house. You go inside and stay there for a while, wandering back and forth and settling where you like and discovering how the room and corridors relate to each other, how the world outside is altered by being viewed from these windows. And you, the visitor, the reader, are altered as well by being in this enclosed space, whether it is ample and easy or full of crooked turns, or sparsely or opulently furnished. You can go back again and again, and the house, the story, always contains more than you saw the last time. It also has a sturdy sense of itself of being built out of its own necessity, not just to shelter or beguile you. (Munro, 1997, Introduction to the Vintage Edition, para. 31).

4.0 Introduction

Munro (1997) uses the analogy of a house to explain how she understands ‘a story’, and this resonated with my own understanding and experience of the interpretative phenomenology process. With each interview, I entered a different story, a different house. A house with a different view from each window. Each time I went back to reread a transcript, it always contained “more than [I] saw the last time”, and I, “the visitor, the reader, [was] altered as well by being in this enclosed space”.

I begin this chapter by outlining the aim and objectives of this research. I then briefly outline the philosophical underpinnings of the phenomenological approach, and
consider interpretative phenomenological analysis (IPA) and how one goes about ‘doing’ IPA. This is followed by a discussion of the various processes I engaged in during the course of this project (i.e., gaining ethics approval, recruiting participants, developing the interview questions and data collection, analysis and the process of reflection).

4.1 Research aim and objectives

The overarching aim of this research was to explore the lived experience of organ transplantation from the perspective of recipients and prospective recipients. Within this broader framework I sought to explore particular aspects of the transplant experience, and this gave rise to the primary objectives of the study.

Much research attests to the dominance of gift-of-life discourse in the sphere of organ transplantation (Fox & Swazey, 2002; Lauritzen et al., 2001; Sharp, 2001; Shaw, 2012, Shaw et al., 2012; Southern & Dickinson, 2011; Svenaes, 2010), and one of the primary objectives of this research was to explore participants’ understanding of gift-of-life discourse: How did they think/feel about organ transplantation being discussed and ‘promoted’ in this manner?; Did they think of their donated heart/liver/kidney as the ‘gift-of-life’?; What meaning/s did this hold for them?; Did this influence how they lived their life post-transplant?; If so, in what ways?

Gift exchange theory (GET; Mauss, 1970) is often employed as a guiding framework for the conceptualisation of organ transplantation. GET is premised on three principles: the obligation to give, the obligation to receive, and the obligation to reciprocate. Receipt of a donated organ (i.e., the ‘gift-of-life’) elicits the obligation to reciprocate. That is, those who receive ‘a gift’ of such magnitude are expected to reciprocate by, at the very least, being grateful. This led to the second objective of this
research, which was to explore the concept of gratitude in the context of organ transplantation: Did participants feel grateful for their organ transplant?; If so, to whom and for what (exactly) did they feel grateful?; Did participants feel grateful in relation to other aspects of their lives?; How did gratitude manifest in their lives (e.g., did it lead to involvement in activities, such as support groups, that represented ‘giving back’ and fostered social connections?); If participants did not feel grateful for their organ transplant, what emotions did the organ transplant raise for them? (e.g., obligation, indebtedness, other emotions?)

Much of the gratitude research to date is based on self-report research within university student populations. This type of research informs knowledge of gratitude in an abstract sense (i.e., gratitude as a positive emotion) but does not necessarily shed light on the experience of gratitude. While I do not wish to detract from the value of this research, it is somewhat limited in its purview. This brought me to the third objective of this study: to explore gratitude in a ‘different’ (i.e., chronically ill) population in order to add to the general body of knowledge concerning the experience of gratitude.

4.2 Phenomenology: The philosophy underlying the interpretative phenomenological approach

IPA has its roots in the philosophies of Edmund Husserl (1859-1938), Maurice Merleau-Ponty (1908-1961), and Martin Heidegger (1889-1976). Husserl emphasised the intentionality of human consciousness, and considered it worthy of scientific investigation (Lopez & Willis, 2004). In his call “Zu den Sachen selbst” (to the things themselves), he outlined the central principle and orientation of phenomenology; our
realities as human beings are experiential (i.e., formed through conscious acts, experienced in, and as, engagement with other human beings and other things), and knowledge must be grounded in contact with this experiential realm (Wertz et al., 2011).

4.2.1 Husserl’s descriptive phenomenology

Husserl’s phenomenological approach is a descriptive endeavour, aimed at providing descriptive categories of the ‘perceived’ world found in participants’ narratives. One of the key features of this approach is the need for the researcher to set aside (bracket) all prior knowledge of a subject, including personal assumptions and biases, in order to “be freshly present to the current instance” of the phenomenon being studied (Giorgi & Giorgi, 2008, p. 170). The aim of bracketing prior knowledge is the achievement of transcendental subjectivity: the ‘neutralising’ of the researcher’s assumptions and biases so they do not influence the object of study (Lopez & Willis, 2004). Key to descriptive phenomenology, also, is the idea that any particular experience has ‘universal essences’ (i.e., features common to all those who experience it) that represent the true nature of the experience. These common features need to be identified in order to form a generalised description of the experience. This highlights the understanding in Husserlian phenomenology that there is a ‘correct’ (or ‘true’) interpretation that can be found when examining a particular experience (Lopez & Willis, 2004).

4.2.2 Merleau-Ponty’s existential phenomenology

The existential phenomenology of Merleau-Ponty has been considered useful in understanding the alterations to embodiment and personal identity that occur as a consequence of transplantation (Edgar, 2009; Mauthner et al., 2014; Shildrick, 2008;
Shildrick, McKeever, Abbey, Poole, & Ross, 2009; Zeiler, 2009). From Merleau-Ponty’s perspective, the body is not merely a “biomedically manipulable housing of self”, and one’s sense of identity is not merely “a matter of mind”: instead, “the materiality of flesh and blood is inseparable from the question, ‘Who am I?’” (Shildrick et al., 2009, p. 35-36). Contemporary (i.e., mechanistic) understandings of the human body and transplantation, suggest that a failing (‘broken’) body part can be replaced by a healthy (‘working’) part, without major disruption to the corporeal self. This assumption has been challenged (e.g., Edgar, 2009; Zeiler, 2009), with Shildrick, McKeever, Abbey, Poole, and Ross (2009) arguing that modification of the body at such a profound level will “inevitably change” a person’s sense of identity and being-in-the-world (p. 37).

Transplantation is often viewed as being unconditionally beneficial and effective, however this perspective is not necessarily reflected in the experience of those who receive a transplant (Edgar, 2009; Mauthner et al., 2014; Shildrick et al., 2009; Zeiler, 2009). A permanent injury or disability shifts the entire basis from which a person, thereafter, engages with the world (Edgar, 2009). A phenomenological approach to the study of organ transplantation can offer valuable insights into the experience of receiving a donated organ, with the potential for these insights to lead to the development of new interventions that improve pre- and post-transplant treatment and care (Mauthner et al., 2014; Shildrick et al., 2009).

4.2.3 Heidegger’s interpretive phenomenology

Central to Heidegger’s philosophy is the understanding of Dasein (i.e., being-in-the-world). Rather than consciousness, he emphasised the embeddedness of human subjective experience in the world. As individuals, we cannot extricate ourselves from the
social/cultural/political milieu in which we exist, and cannot, therefore, know ourselves (or others) in any way separate from ‘being-in-the-world’ (Eatough & Smith, 2008). In the research context, being-in-the-world does not apply only to those being studied; the researcher can no more bracket his/her prior knowledge and social/cultural assumptions and biases than the participant can. One of the key underpinnings of Heidegger’s philosophy is that phenomenology is always hermeneutic; it delivers an interpretation of a subject’s being-in-the-world, guided by the interpreter’s being-in-the-world (his/her historically/culturally embedded ways of thinking).

In contrast to descriptive phenomenology, the interpretive approach requires prior knowledge of the phenomenon being studied (Giorgi & Giorgi, 2008). There are many angles from which an object of study can be approached, and prior knowledge is needed to determine an appropriate focus for exploration and analysis of a particular phenomenon. The researcher consults existing literature, and examines methodological alternatives in order to determine the perspective of analysis (Giorgi & Giorgi, 2008). The researcher’s prior understanding of a phenomenon might lead him/her to be more responsive to particular aspects of the data, which could influence the shaping of interpretive frameworks and lead to certain themes being given priority over others (Brocki & Wearden, 2006). However, it is not possible to ‘bracket out’ one’s own perspective and as Smith (2004) has argued, the interpreter’s ‘expert’ knowledge is valuable in terms of both guiding a study, and undertaking deep interpretation of participants’ narratives.

Meaning is embedded in common practices, and this understanding undergirds the hermeneutic (interpretive) phenomenological approach (Lopez & Willis, 2004). These
meanings, understood in the context of the individual’s narrative, are what interest interpretive phenomenological researchers. Lopez and Willis (2004) highlighted co-constitutionality as one of the important concepts undergirding Heidegger’s philosophy; the meanings derived via the interpretive process are co-constituted by the participant and the researcher in the context of a study. In contrast to Husserl’s approach, there is no, one, ‘true’ interpretation (or answer) to be found; there can be more than one interpretation, depending on the focus of the study. Research based on an interpretive phenomenological approach, thus, aims to provide a coherent and legitimate account of the phenomenon in question that is perceptive to participants’ expressed reality (Pringle et al., 2011).

4.3 Interpretative phenomenological analysis (IPA), and health

There has been an increasing interest in the development and use of qualitative research methods to investigate illness experiences across the past two decades (Biggerstaff & Thompson, 2008; Lyons, 2011; Ring, Gross, & McColl, 2010; Smith, 2004; Stainton-Rogers & Willig, 2008). Qualitative approaches widen the scope of questions that can be asked about the nature of health and illness, allowing examination of the complexities of health and illness, and also the psychosocial issues that underlie these experiences (Chamberlain & Murray, 2008). The unique understandings that can be gleaned via qualitative approaches are essential to improvements in clinical knowledge and quality of care (Collingridge & Gantt, 2008).

Qualitative approaches bring ‘real life’ into health psychology. Theory and theoretical models are important to the study of health and illness. However, these concepts and models need to be more critically utilised, with more curiosity for, and closer attention to, real-life behaviour in real-life samples (Kaptein, 2011). Sardonically
refuting the necessity for more theory-driven research (in their OFF theory of research utilisation), Oxman, Fretheim, and Flottorp (2005) encourage “less rather than more focus on high-level theories, less rather than more jargon, less dogmatism, more common sense, less theoretical work and more rigorous evaluations that include direct measurement of important outcomes” (p. 115). As contended by Shaw (2011b), this pragmatic approach does not in any way imply that qualitative research is just common sense. It, instead, suggests that survey methods (and others cited within the ‘scientific model’) do not represent the only way of conducting valid research. Qualitative methods are better suited to the answering of some kinds of research questions, and all stakeholders are better served by adopting the approach (qualitative or quantitative) that is better placed to answer the particular question being asked (Shaw, 2011b). It is with Oxman et al.’s ‘call to arms’ in mind, that I undertook the current research.

IPA is a specific approach to qualitative research: one that has been developed and articulated by Jonathan Smith since the mid-1990s (Eatough & Smith, 2008; Smith, 2004). It is a particularly relevant choice for researchers engaging in a detailed examination of lived experience, especially how a person ascribes meaning to, and makes sense of, a specific experience (Smith, 2011). As reported by Smith (2011) in his review of IPA studies conducted between 1996 and 2008, illness experiences are the largest specific area of study utilising the IPA approach. The attention to the ‘real life’ of illness experience can be seen in the diversity of these experiences of interest to IPA researchers, including (for example): living with dementia in residential care (Clare, Rowlands, Bruce, Surr, & Downs, 2008); the embodiment of artificial limbs (Murray, 2004); what it is like to live with Parkinson’s disease (Bramley & Eatough, 2005); vulnerability to heart
disease (Senior, Smith, Michie, & Marteau, 2002); the experience of chronic pulmonary
disease (Seamark, Blake, & Seamark, 2004); what it is like to experience the stigma
associated with being schizophrenic (Knight, Wykes, & Hayward, 2003); participation in
a pro-anorexia internet site and its influence on disordered eating (Mulveen & Hepworth,
2006); hope in relation to the experience of psychosis (Perry, Taylor, & Shaw, 2007);
what it is like to experience brain injury (Howes, Benton, & Edwards, 2005); what it is to
like to care for someone who has survived a stroke (Hunt & Smith, 2004); the experience
of parenting an adolescent with complex chronic pain (Jordan, Eccleston, & Osborn,
2007); coping in women with HIV (Mayers, Naples, & Nilsen, 2005); and the experience
of living with chronic fatigue syndrome (Dickson, Knussen, & Flowers, 2007).

When studying the experience of illness, the value of applying a strictly
biomedical model of illness (“where an observable bodily process is held to map onto a
predictable illness experience in a fairly simple way”) is questionable (Brocki &
Wearden, 2006, p. 88). As emphasised by Kaptein (2011), participants attend to the
‘messy complexity’ of an experience when they tell their story: they emphasise the
aspects of the experience that are important to them as opposed to being forced to contain
the experience within the pre-determined confines of a Likert-scale questionnaire. The
illness experience is constructed (i.e., we actively create, rather than passively receive,
reality), and it is therefore, important to understand illness from the perspective of those
experiencing it (Brocki & Wearden, 2006). The interpretive phenomenological approach
may thus be regarded as efficacious to the study of illness experience.
4.4 ‘Doing’ IPA

IPA is an idiographic approach that privileges the individual, and recognises the active role of the analyst in accessing an in-depth account of a particular experience (Pringle et al., 2011; Smith, 2004). These accounts of experience are typically encountered in the context of interviews. However, there is no *a priori* requirement for this particular mode of data collection, and other methods (such as diaries or personal accounts) can be utilised in the context of an IPA study (Eatough & Smith, 2008). The participant’s story lies at the heart of IPA, and careful listening to it is paramount in this context. As noted by Pringle et al. (2011), the researcher accepts the participant’s story (rather than being ‘suspicious’ of it) but does so in a questioning way. Needless to say, the researcher does not have direct access to the thoughts and feelings that make up the participant’s experience: he/she thus engages in a double hermeneutic in the process of IPA. That is, he/she attempts to make sense of how a participant is making sense of his/her experience (Smith, 2011).

IPA involves an iterative inductive approach to analysis. Analysis begins with the close reading of each participant’s narrative (noting initial themes, and ensuring that each person receives ‘full justice’); proceeds via the re-readings of narratives/extracts, and intra- and inter-individual case analyses (where interconnected and recurring themes are noted and described); and is finalised with the construction of a narrative that incorporates the meanings made, by both the participants and the researcher/s, of the subject under investigation (Eatough & Smith, 2008). Throughout this process, care needs to be taken to ensure that themes remain firmly grounded in participants’ narratives. The research account should be rich and transparent, including direct quotes (in order to
substantiate findings), and findings are explicated in terms of their relevance to current literature, so that readers can evaluate the extent to which they are transferrable to other groups (Pringle et al, 2011; Smith, 2011; Smith, Flowers, & Larkin, 2009). Smith et al. (2009) argue that IPA research is not served best by a focus on commonalities alone. Good IPA research is characterised by the capturing of both convergence and divergence across themes. The idiographic approach entailed in IPA (i.e., a rich, in-depth account of each participant’s experience) requires intensive work and commitment to the IPA process on the part of the researcher. With regards sample size, ‘less is more’ in IPA research, as it is only possible to undertake the detailed, nuanced, analysis entailed in IPA with smaller samples (Reid, Flowers, & Larkin, 2005).

4.5 Method

4.5.1 Ethics, and the research proposal for this project

I sought ethics approval from the university ethics committee after conducting preliminary research to identify some of the gaps in knowledge relating to psychosocial aspects of transplantation (and gratitude), and engaging in lengthy discussions with nurse practitioners at two large metropolitan hospitals in Western Australia (i.e., Royal Perth Hospital, where all heart transplants in the state are conducted, and some kidney transplants; and Sir Charles Gairdner Hospital, where all liver transplants in the state are conducted, and some kidney transplants). I had anticipated that participant welfare might be of concern to the ethics committees, and in the ethics application I stated what would be done in the advent of participants experiencing negative side effects. That is, I would telephone each participant two days after the interview to monitor their emotional coping
(this was later revised to a telephone call the day after the interview). Counselling, through the university’s counselling clinic, would be provided to any participant who experienced discomfort or anxiety as a consequence of being interviewed.

Despite outlining support options for participants, which showed that I recognised the potential for psychological distress, the hospital ethics committees considered I had ‘somewhat understated’ the potential for psychological distress to emerge as a consequence of participation. I was asked to provide participants with at least two additional support options: a service that would provide ‘acute care’ (in the event that someone needed immediate counselling), and also one that provided a 24-hour service. Each of the hospital ethics committees requested that I provide the details of support services (e.g., psychology and social welfare) available within the hospital. I was also asked if it was possible for the aim of the study (i.e., to explore how participants experience and make meaning of transplantation) to be met via a ‘purely observational’ method. The committee asked, if I believed I could not do this, how I would ‘ethically manage’ the potential impact of the study on participants’ emotional well-being, quality of life and future decision making.

From my experience, it appears the hospital ethics committees (dealing, for the most part, with quantitative research) may have little exposure to the use of IPA in health related research, and consequently might be unfamiliar with its epistemological underpinnings and rigour. This was made evident in the request that I might utilise a ‘purely observational’ method to gain insight into the meanings that recipients/donors make of their transplant experience. I could observe whether a participant was attending appointments (or not), was employed (or not), was engaging with others around them (or
not), and whether (or not) they were engaging in many other behaviours. However, I was at a loss to understand how I could learn what any of these behaviours mean to participants, and their experience of transplantation, by merely observing them. I was also perplexed by how I might ‘ethically manage’ participants’ emotional well-being, quality of life and future decision-making. Participating in research might well have an influence on well-being, quality of life and/or future decision-making, but I found myself contemplating if it is possible for any researcher, regardless of methodological affinity, to ‘manage’ these phenomena. Ethical guidelines developed in the context of experimental biomedical research, are largely silent on many issues relevant to interpretive and interactive qualitative research methods (Christians, 2011), and it has been suggested that ethics committees reviewing qualitative research proposals should be comprised of experienced qualitative researchers or, at a minimum, include such researchers on these committees (Brinkmann & Kvale, 2008).

Ethical issues are inherent in any research concerned with the private lives of others, and the placing of participants’ accounts in the public sphere (Brinkmann & Kvale, 2008). Qualitative researchers, like quantitative researchers, must adhere to the principle of beneficence (among others) when conducting research -- the risk of harm to participants must be minimised as much as possible. However, Orb, Eisenhauer and Wynaden (2000) caution against the adoption of a paternalistic approach whereby the voices of certain individuals are silenced because ethics committees decide these individuals are potentially ‘too vulnerable’ to talk about their experiences. Individuals in these ‘too vulnerable’ groups are denied autonomy and freedom of choice when decisions regarding participation are made for them. Dyregrov et al. (2011) noted that ethics
committees ‘too often’ delay or stop studies on the basis of the *presumed* vulnerability of the intended sample. In their study of individuals bereaved by suicide, they found that the majority of participants described their participation in the study as ‘unambiguously’ positive. A substantial minority reported that although they found the experience of participation ‘painful’, it was a positive experience overall. Participants reported positive aspects of participation as: the opportunity to vent their thoughts and feelings (e.g., sadness, anger); the opportunity to put their experience into words; the opportunity to talk to an ‘outsider’ about their experience; increased insight; new perspectives; easing of guilt; the opportunity to contribute to research/knowledge; and the opportunity to help/support others in a similar situation.

The absence of discussion and opportunities to talk about certain aspects of the transplant experience might produce anxiety for some organ donor family members and transplant recipients (Shaw, 2011a). Shaw (2011a) found that talking about their transplantation experience (including elements such as the decision-making processes involved in deciding whether or not to donate the organs of a family member, or attempting to write letters to donor families) to an empathic listener in a safe and non-judgmental context, fostered coping and had an anti-shaming effect on participants in her study. She emphasised that by ‘allowing’ participants to talk about the issues that concern them, we acknowledge the legitimacy of their concerns and anxieties, which can lead to improved psychosocial outcomes. Others (e.g., Dyregrov, 2004; Hawton, Houston, Malmberg, & Simkin, 2003; Hynson, Aroni, Bauld, & Sawyer, 2006; Jorm, Kelly, & Morgan, 2007) have similarly reported the (potential) benefits of participating in qualitative research studies. Although due care must be taken to minimise the risk of
harm to participants, it is important that ethics boards do not unnecessarily restrict research involving ‘vulnerable’ populations (Dyregrov, et al., 2011).

4.5.2 Participants

Participants were recruited from Royal Perth Hospital and Sir Charles Gairdner Hospital in Western Australia. Nurse practitioners employed by the respective hospitals provided me with a list of potential participants (i.e., those residing within Western Australia, who the nurse practitioners deemed healthy enough to participate in an interview), and I mailed a Participant Information Sheet and an Invitation to Participate to all those on the list. Letters were addressed at each of the hospitals, under the supervision of a nurse practitioner, and were mailed through the hospitals’ mail system. This ensured that I did not leave the hospitals with any patient information.

Participants in the research on which this thesis is based were 30 organ recipients or prospective recipients. Of the recipients/prospective recipients, there were 13 heart and 6 liver recipients, and 1 liver and 10 kidney prospective recipients (all of who were on transplant waitlists). Only one of the prospective recipients (a man on the kidney waitlist) received a transplant during the course of the study, and he was interviewed a second time. I interviewed all bar one of the heart recipients a second time (when I telephoned one woman requesting a second interview, she stated that she was recovering from a bad cold/flu and did not feel well enough to participate).

In the original conception and formulation of this research, I had anticipated including donors’ experiences of transplantation (as well as those of recipients), and the research proposal sent to ethics committees therefore included recruitment of transplant donors and potential donors. Three potential donors (a woman who would be donating to
her husband, a woman who would be donating to her son, and a man who was a potential altruistic donor) responded to the invitation to participate, and were interviewed. As the study evolved, though, recipient experiences of transplantation became the focus of attention and analysis. Preliminary analysis of the potential donors’ interviews has been undertaken. However, in the absence of in-depth analysis, it would be premature (and ethically/morally irresponsible) to report on this data herein. It has therefore not been included, and will be analysed and reported separately. The final data corpus for this thesis is, thus, comprised of 42 interviews (i.e., heart/kidney/liver recipients and prospective recipients), ranging from approximately 20 minutes (i.e., a ‘follow-up’ interview) to 2 hours and 15 minutes in length. The average length of the initial interviews was 56 minutes, and the average length of the follow-up interviews was 37 minutes.

4.5.3 Data collection

Data were collected via semi-structured interviews, deemed the ‘exemplary method’ of data collection for IPA (Smith, 2004; Smith & Osborn, 2003). Eatough and Smith (2008) stressed the importance of achieving the right balance when conducting semi-structured interviews, with pre-determined questions used to guide, rather than dictate, the direction of the interview, so that participants have a ‘strong say’ in how the interview proceeds. A schedule of interview questions, thus, does not have to be rigidly adhered to through the course of semi-structured interviews. Questions can be altered in relation to participants’ responses, and the researcher has the freedom to pursue interesting/important subjects that arise (Chapman & Smith, 2002). This is an important way for the interviewer to convey to participants that he/she is really listening to their particular story, and is not trying to fit them into a preconceived structure.
In the present research, participants read through and signed the consent form at the outset of the interview. I asked them if they had any questions about anything covered in the form, or the Participant Information Sheet, which broadly outlined the type of questions that would be asked (e.g., circumstances that led to transplant/or the decision to donate; thoughts and feelings in relation to current circumstances; and future expectations being on the waitlist/or having received a transplant) so that participants would have some idea of what the interview would entail. This was followed by some factual questions regarding their age, and when they had received their heart/liver/kidney (in the case of recipients) or how long they had been on the waitlist (in the case of prospective recipients). I then began the interview proper, with the first prompt question (outlined below). All interviews were audio-recorded, and the recordings were transcribed verbatim.

4.5.4 Schedule of interview questions

I developed a Schedule of Interview Questions (see Appendix A) to facilitate disclosure (Fontana & Frey, 2000), for which I had received ethics approval. The schedule comprised a maximum of eight questions, but all eight were seldom used as most participants addressed some of the questions without being asked directly. The interview questions were designed in keeping with Smith and Osborn’s (2003) stated aim of IPA research, that is, to explore flexibly, and in detail, the subject of interest. I was interested to learn about participants’ experiences of transplantation in a broad sense (i.e., how they thought and felt about transplantation, and what it was like to ‘live’ this experience) and also, more specifically, I was interested in learning about their experience of gratitude.
(generally, and in direct relation to their transplant), their understanding of transplant as the gift-of-life, and any feelings of indebtedness and/or obligation.

Questions regarding gift-of-life, gratitude and indebtedness were informed by early reading of the literature regarding gratitude (e.g., Emmons & Crumpler, 2000; Watkins et al., 2006) and transplantation (e.g., Fox & Swazey, 2002; Siminoff & Chillag, 1999). This preliminary reading of the literature was sufficient to gain a broad understanding of both gratitude and transplantation. An in-depth reading of the literature was undertaken after initial analysis of the individual transcripts to engage in a deeper level of interpretation, congruent with IPA (Smith, 2004).

I began the interview proper with a broad question (i.e., Can you tell me something about the circumstances that led to you being placed on the transplant waitlist?), designed to give participants a ‘starting point’ (somewhere to begin their story) and also to enable them to settle into the interview and feel comfortable speaking with me. I let participants know that I was interested in hearing about their experience of transplantation (i.e., what it has been like for you). Most participants talked about many years of illness (and treatment), and the realisation at some point that transplantation was ‘inevitable’ if they were to survive organ failure. Many continued telling their story without prompting (e.g., talking about their time on the transplant waitlist, receiving a transplant, and the effect transplantation had on their lives).

The remaining questions on the interview schedule were used as prompts when participants did not broach a particular area of interest. For example, gratitude (i.e., Is there anything in your life right now for which you are thankful or grateful?) and the gift-
of-life (i.e. In the media, transplantation is often talked about as a ‘gift’ or the ‘gift of life’. Can you tell me your thoughts and feelings in relation to this?)

It was evident, during the interviews, that many participants were engaged in the telling of their story. They spoke at length about both the positive and negative aspects of their experience, and encouraged me to extend the interview -- many times, as an interview was coming to a close, I was asked if I had any other questions, and on several occasions participants thought of something else they wished to talk about at this point, and extended the interview in this way. All participants, bar one, agreed without hesitation to a second interview, and several offered to participate in any future research (in relation to transplantation) that I might undertake. As noted previously (Dyregrov et al., 2011; Shaw, 2011a), participation in research can be beneficial for participants in a number of ways, including the opportunity to tell their story, and the opportunity for them to reciprocate (i.e., give back to the community from which they have drawn). This was evident in the context of the present research. Many participants expressed their thanks for the opportunity to talk about their experience, and many also stated that they were participating in the study in the hope that the telling of their story might help those who experience transplantation in the future.

4.5.5 The ‘process’ of reflection

As emphasised by Shaw (2011a), the interviewer is not left unaffected by the process of interviewing those who have some experience of transplantation. I kept a reflexive journal throughout the period of data collection and analysis, and noted particular thoughts and emotions that arose in response to the participants and their interviews (initially) and readings of the transcripts (later). Participants were the source of much
questioning of myself, and the preconceptions that I was bringing to the analysis of their narratives. I will use the example of ‘Doug’ to help illustrate my point here (quotes from Doug are included in the article based on liver recipients’ experience of transplantation; O’Brien, Donaghue & Walker, under review).

Doug had received two liver transplants; the first one he described as “a disaster”, and he reported that “[i]f I hadn’t got [the second transplant], I would have died probably. A week or two weeks later. I was going downhill. I was leaking everywhere”. He stated that the second time around “[he] got a good one, and it’s been good ever since”. Doug reported on the cost of his transplant treatment (including two transplant surgeries, the extended stay in hospital following the first transplant – “in and out of ICU”, “all the aftercare”, and “subsidised meds”), and put the cost at a “six figure sum”. He later reported on other illnesses he had experienced, over a period of several years, which required extensive treatment (including surgical intervention in several instances).

Immediately after the interview, and during the first reading of Doug’s transcript, I noted, several times, the level of anger apparent in Doug’s telling of these events. I noted also that he did not seem to focus on the extent of medical treatment he had received, but rather on the ‘poor quality’ of help received post-transplant. For example, while Doug spoke of his medical treatments (in, at times, what appeared to be a cursory manner), he spoke at great length of the ‘failure’ of government support agencies to provide ‘satisfactory’ housing. In my journal, I questioned why, in light of all the (life-saving) treatment he had received, it was the emotion of anger that appeared to dominate much of his interview. He had reported the extent of treatment received at the expense of the Australian health system, and I questioned why he seemed to experience little
gratitude in relation to this. This gave rise to questions about my own questions. Was there a sense of judgment lurking in my responses to Doug, and the transcript of his interview? I had read about gratitude in the context of transplantation: was I a part of the ‘general consensus’ that gratitude should be experienced in relation to the gift of life? I thought I had left preconceptions about gratitude in this context aside, but it seems that might not have been the case. My reflections indicated, to me, that I might have (after all) expected to ‘see’ gratitude in those who had received a transplant.

I read extracts from Doug’s transcript again (with this new awareness). In these re-readings I noted something that had not caught my attention previously. Was Doug’s anger masking another, deeper, emotion? Was there perhaps a sense of despair running throughout his narrative? Extracts were read again, and I could more clearly see that Doug’s recounting of the treatment he had received for a range of diseases/disorders over a number of years was not a mere litany of his illnesses (and associated treatment), but instead a deeply personal account of despair, based on many years of illness and the slow extinction of hope for the life he would have wanted but had not achieved. I read again the extracts in which Doug talked about the outcome of years of ill health; in particular those in which he referred to his aim in life to take care of his wife and son. I questioned whether Doug might be feeling shame about not being able to support his wife and son in a way he understood as being appropriate.

It was at this time that I read material regarding shame, and its connection with anger (e.g., Brown, 2006; Dearing, Stuewig, & Tangney, 2005; Ferguson, Eyre, & Ashbaker, 2000; Tangney, Stuewig, & Mashek, 2007). In my bid to understand Doug’s experience of transplantation, I came to believe that shame might underlie his experience
of illness (and transplantation), expressed in his anger about being dealt with unfairly by support agencies. As suggested by Collins and Nicolson (2002), I reread the entire transcript once more to verify that my interpretation (of Doug’s shame) was indeed grounded in his account of transplantation.

4.5.6 Rigour

Qualitative and quantitative research methodologies each have their own standards by which to assess the rigour of the research that falls within their respective paradigms. There is little to be gained by attempting to assess the merits of one, using the criteria of the other (Collingridge & Gantt, 2008). Rigour in qualitative research is established by demonstrating credibility, transferability and dependability (Koch, 2006).

The researcher’s self-awareness is critical to the credibility of qualitative research, and engaging in a reflexive process (e.g., keeping a journal) is one way of increasing self-awareness (Koch, 2006). As outlined previously, I engaged in such a process across the course of this research. The provision of sufficient contextual information, in journal articles based on research, allows those evaluating the research to assess transferability of findings (Koch, 2006). Verbatim extracts, as exemplars of themes, ‘ground’ findings in examples, and also provide the reader with a source from which to make his/her assessment of the interpretations made (Brocki & Wearden, 2006).

Auditing of data and analysis helps to ensure that the final account derived from the data is a credible one, and auditing is one of the ways in which dependability might be established (Pringle et al., 2011). My supervisor conducted audits across a number of meetings, where all aspects of analysis, including reading/s of the transcripts, identification of themes, illustrative quotes, and my reflections, were discussed.
4.5.7 Completion of analysis

All interviews/transcripts were dealt with in the manner outlined above (for Doug), and then connections across the individual cases were made. Analysis was completed with the development of a set of superordinate themes (Chapman & Smith, 2002) representing the experience of transplantation from the perspective of participants in this research. These themes were presented across three journal articles that comprise the following three chapters. Respectively, *Deservingness and gratitude in the context of heart transplantation*; “It’s not a miracle, it’s simply good medicine”: The lived experience of liver transplantation; and *The experience of kidney transplantation: Hope for the ‘gift of freedom’*. 
CHAPTER FIVE

Deservingness and gratitude in the context of heart transplantation

5.0 Relationship of the paper to the thesis

The thesis represents an exploration of the experience of organ transplantation, with a particular focus on gift-of-life understandings of transplantation and the experience of gratitude in this context. In this chapter, I present a paper in which I have outlined my findings in relation to the experience of heart transplantation.

Gift-of-life discourse accentuates the enormity of ‘the gift’ received in the context of transplantation, and my interpretative phenomenological analysis of the interview data indicated that deservingness was a concern for participants. Many attempted to establish their deservingness of their heart transplant, a rare and precious gift. Gift-of-life discourse influences the meaning/s that heart recipients make of their transplant experience, and the implications of this are discussed here.

The paper, titled Deservingness and gratitude in the context of heart transplantation, was published in Qualitative Health Research in September 2014.
5.1 Abstract

Heart transplantation is now routinely offered as a treatment for end-stage heart failure, and the “gift-of-life” metaphor has become pervasive in this context, forming the foundation on which transplantation discourses rest. In this article, we question organ-as-gift understandings of transplantation. One can also legitimately think of the transplanted organ as a donation, with distinct implications in terms of the transplantation experience for the recipient. We explored the transplantation experience of 13 heart recipients in Australia. We conducted semistructured interviews, and our interpretative phenomenological analysis of the data resulted in three themes: deservingness; nuances of gratitude; and giving forward. Our results indicate that differences between organ-as-gift and organ-as-donation understandings of transplantation are more than merely semantic. Organ-as-donation understandings raise the issue of deservingness, with recipients’ assessments of their worthiness influencing the recipients’ posttransplant experience of gratitude and, ultimately, the meaning(s) gleaned from their transplant experiences.
5.2 Introduction

Even the idea of a pure gift is a contradiction. (Douglas, 1992, p. 156).

Organ transplantation is no longer a novel event in many Western societies, and social constructions in relation to the procedure and experience of transplantation have emerged within both the medical world and the wider community. One can conceptualize the exchange that occurs in the context of transplantation as a gift, and this has given rise to the prevailing gift-of-life discourse, premised on the idea that the donated organ translates to the “gift of life” itself (Fox & Swazey, 2002). Fox and Swazey argued that this concept has become so pervasive that it forms the foundation on which all transplantation discourses rest (i.e., medical, organ procurement agencies, and the general public). Research, though, has indicated that gift discourse fails to encompass the myriad psychosocial complexities involved in the transfer of an organ from one person to another (Shaw, 2010; Shaw, Bell, & Webb, 2012). Indeed, Shaw (2012) argued that those using gift-of-life rhetoric engage organ recipients in a prescribed experience of transplantation, directing the experience itself and also the recipients’ moral reckoning of it.

Researchers have suggested that the organs made available for life-saving transplantations might be better thought of in a different light, perhaps as donations rather than gifts (e.g., Siminoff & Chillag, 1999). Both understandings are found in social discourses around organ transplantation, and although this distinction might seem purely semantic, we contend that it has distinct implications that can be powerfully consequential for the ways in which the actions and experiences of organ recipients find
meaning. In this article, we report an analysis of interviews with 13 heart transplant patients to explore how the lived experiences of organ transplantation are grounded in social discourses concerning organ donation, the gift of life, and gratitude.

5.3 Gifts versus donations

Given the dominance of the gift-of-life discourse, some have proffered gift exchange theory (GET; Mauss, 1970) as a potential framework for conceptualizing organ transplantation as a process in which a gift (i.e., organ) is given and received (Sque & Payne, 1994). Mauss (1970) developed GET on the basis of research conducted within preindustrial societies of the American Northwest, Melanesia, and Polynesia, and although some have questioned the relevance of Mauss’s gift concept in the context of contemporary societies (Sque, Payne, & Macleod Clark, 2006), others have widely adopted GET in the forum of transplantation research (Fox & Swazey, 2002; Siminoff & Chillag, 1999). The basic premise underlying GET is that gift exchange is a form of social contract governed by three interlocking principles: the obligation to give, the obligation to receive, and the obligation to reciprocate (Mauss, 1970). Gift exchanges are understood as part of the initiation and perpetuation of ongoing relationships.

Putting to one side the social pressures that shape the apparently “free” gift exchange, one of the most problematic features of seeing organ donation in terms of a gift metaphor is the issue of reciprocity. As the donor of the organ is no longer alive, the recipient cannot directly repay the indebtedness incurred via the receipt of the gift. Although other actions could potentially assuage indebtedness, such as contact with the donor family to show how the transplanted organ has allowed the recipient to continue to live a full life, or efforts to “pay it forward” through altruistic acts for other people, none
of these can sufficiently reciprocate for the enormity of the gift of life. Fox and Swazey (2002) coined the phrase “tyranny of the gift” to describe the high psychological and moral cost borne by many recipients who struggle to reciprocate in a manner considered sufficient.

Research has indicated that the gift-of-life metaphor is exploited in the context of transplantation (i.e., in a bid to manipulate recipients’ behavior and as a mechanism for increasing donation rates) and that there might be alternatives that better represent the realities of organ transplantation, with fewer detrimental outcomes for recipients (Lauritzen, McClure, Smith, & Trew, 2001; Siminoff & Chillag, 1999). Conceptualizing the organ as a donation rather than a gift might be such an alternative. According to Douglas (1992), a gift and a donation are not one and the same; a gift engages the requirement for reciprocation, a donation does not. Although some of the specific burdens entailed by gift discourse might be addressed via a shift to donation discourse, we argue that receiving a donation introduces its own set of moral requirements that need to be managed, specifically, of deserving or being worthy of the donation (e.g., Morgan, Harrison, Afifi, Long, & Stephenson, 2008). This requirement seems particularly salient in circumstances such as those around heart transplantation, in which there are far fewer organs available for transplant than there are recipients in need.

A focus on being the beneficiary of such a valuable donation might shift the moral responsibility felt by the recipient toward the need to establish his or her deservingness, especially in relation to others who might have benefited from the donation. If, as Douglas (1992) claimed, the terms donation and gift describe quite different situations, their interchangeable use in social discourses around transplantation is problematic.
Recipients of transplanted organs might find themselves in a psychologically precarious predicament as they attempt to come to understand the social and moral obligations attached to their situation. Recipients could perceive the transplanted organ as both gift, in which case a relationship has been initiated and reciprocation in some form is expected and required, and donation, in which case reciprocation is unwarranted but the deservingness of the recipient must be established.

5.4 Appreciation and Gratitude

One important way an organ recipient can show a correct moral stance in relation to the benefit that he or she has received is by expressing great appreciation and gratitude. Regardless of whether a transplanted organ is understood to be a gift or a donation, it benefits the recipient, who is therefore expected to show gratitude. McCullough, Kilpatrick, Emmons, and Larson (2001) have argued that the moral aspects of gratitude are socially valuable because they facilitate a broad range of pro-social actions by the grateful person. Gratitude might be a particularly beneficial response to the receipt of an organ, as it broadens the possible avenues of response to include a much wider range of actions than the direct, tit-for-tat exchanges that might be expected under a more transactional view (Fredrickson, 2004). In recent years, gratitude scholars have also examined the benefits of gratitude for the person experiencing it. Several studies have tested the effects of gratitude interventions and have shown substantial benefits to health and well-being from practices in which participants are encouraged to reflect on things in their lives for which they are grateful (e.g., Emmons & McCullough, 2003; Lyubomirsky, Dickerhoof, Boehm, & Sheldon, 2011; Seligman, Steen, Park, & Peterson, 2005).
To date, research has not explored whether and how the moral and personal elements of gratitude are experienced among those of whom gratitude is normatively expected: recipients of life-saving organ donations. Our aim in this research was to explore the lived experience of successful heart transplantation, particularly how heart recipients experience and manage “the tyranny of the gift” that Fox and Swazey (2002) proposed. We focused on the role of gratitude in exploring how participants manage their posttransplantation lives and in understanding their moral position in relation to both the donor (and donor family) and other potential recipients of the organ that they received.

5.5 Method

5.5.1 Participants

This article is based on the interviews of 13 heart recipients. Of these, eight were men. Ages ranged from 35 to 72 years ($M = 56.23$). Time since transplant ranged from 10 weeks to 11 years; five of the transplants took place within 1 year of the first interview, and eight took place more than 2 years prior to this interview. Interviewing began in late 2010, and extended over a period of 14 months. The first author interviewed each participant twice (with the exception of one), approximately 8 months apart. She recorded and transcribed all interviews in detail. She assigned participants pseudonyms and altered or omitted some potentially identifying details (such as references to occupations and place names) to preserve confidentiality. These participants formed part of a wider study investigating transplantation across different organs (i.e., heart, liver, and kidney).
5.5.2 Ethics

We recruited heart transplant recipients via the Cardiac Transplant Service (CTS) at a large metropolitan hospital in Australia after ethics approval for the research was received from both Murdoch University Human Research Ethics Committee and the hospital’s ethics committee. The first author mailed an invitation to participate and a participant information sheet (PIS) to all patients of the Transplant Service still residing in Western Australia who had received a heart transplant and who were deemed by a nurse practitioner (employed by the CTS) to be healthy enough to participate in an interview.

The PIS outlined the nature and purpose of the study, participation details (e.g., the type of questions that would be asked; recording of interviews; and approximate length of interviews), possible risks associated with participation (e.g., emotional discomfort, anxiety), processes for assuring privacy and confidentiality, and voluntary participation and withdrawal (i.e., the PIS stated that participants could withdraw at any time, without needing to give a reason, and without any adverse effects on their current or future medical care). The PIS also provided the contact details for the research team and the hospital ethics committee should potential participants wish to seek additional information. The PIS contained directions to those who were interested in participating in the study to contact the first author to arrange an interview at a location that was most convenient for them (i.e., home, the hospital, or the university). At the start of the first interview, each participant signed a consent form, which restated key information from the PIS.

The study was of a sensitive nature, and we considered it important to offer support to participants in case of adverse effects of the interviews. Consequently, at the
end of the first interview, we provided each participant with a laminated card that
outlined contact details for the interviewer, support services at the hospital (i.e.,
psychiatrist or social worker), support services at the university (i.e., psychology clinic),
and two agencies that provided telephone counseling 24 hours a day, 7 days a week. The
interviewer also telephoned each participant the day after each interview took place to
enquire about his or her emotional state and to ask if additional support was needed.
These follow-up telephone calls were, without exception, brief; participants reported no
adverse effects, and many participants expressed their gratitude for the opportunity to talk
about their experiences in a safe (i.e., nonjudgmental) environment.

5.5.3 Schedule of interview questions

We designed the schedule of interview questions for heart recipients with the aim of
gaining insight into the psychological experience of transplantation. Consequently, we
focused on the thoughts and feelings of recipients at various times throughout the
experience (e.g., when they were initially told they needed a transplant, while being tested
for placement on the transplant waitlist, when they received the news that a heart was
available, in the early days after receiving their transplanted heart, over the time since
transplantation); recipients’ thoughts and feelings in relation to their transplanted heart;
general feelings of gratitude/obligation/ indebtedness; how transplantation is talked about
and understood in the media (e.g., gift-of-life discourse); the changes that transplantation
brought about in the lives of recipients; and recipients’ expectations for the future.

The first author conducted all interviews, and each interview began with the
interviewer letting participants know that she was interested in hearing about their
experience of transplantation: “What has it been like for you? Perhaps you could begin by
telling me what led up to you being placed on the waitlist.” This initial prompt helped to alleviate concerns participants might have had about what they “should” talk about; it provided a starting point for their story and the space for them to settle into the interview and feel comfortable with the interviewer.

5.5.4 Approach to analysis
As Sakala, Gyte, Henderson, Neilson, and Horey (2001) discussed, when exploring the psychosocial aspects of a particular illness, the patient is “expert,” with his or her perspective carrying the weight of authority. This study aimed to tap into this expert understanding of transplantation from the perspective of heart recipients. Given this context, we deemed interpretative phenomenological analysis (IPA) to be the most appropriate method of analysis. Biggerstaff and Thompson (2008) have described IPA as a qualitative methodology of choice when investigating illness and associated health care from the perspective of the patient. This methodology allows the exploration of what it is like to live with a particular condition and how individuals ascribe meaning to these experiences. They noted that IPA explicitly makes acknowledgement of the researcher’s engagement with the participant’s narrative, and postulated that this interpretative methodology provides the very means by which it becomes possible to access the participant’s inner world.

Shaw (2011a) discussed the power of discourse in the construction of social realities, highlighting the view that storytelling is a performative event and, in the context of social research, the researcher acts as a co-constructor of the story being told. We found this to be the case in the current study. Participants openly and eagerly welcomed the opportunity to tell their stories; many expressed gratitude to the interviewer for
“allowing” them to tell their stories and for listening to them, acknowledged that they hoped others would benefit as a result of them speaking about their experiences, proffered ideas about ways in which “the system” might be improved, and volunteered to participate in any related research the interviewer might undertake in the future.

Given the level of engagement the interviewer experienced, she kept a reflexive journal throughout the processes of data gathering and analysis. Murphy, Dingwall, Greatbatch, Parker, and Watson (1998) described reflexivity as an awareness of one’s a priori assumptions and the ways in which they could contribute to data collection and subsequent analysis. With a view to developing this awareness, and thereby engaging with the participants (during the interviews) and their transcriptions (during analysis) more openly, the interviewer noted her thoughts, emotional responses, observations, and questions in relation to the participants, their stories, and the transcribed texts.

We followed the process of IPA Willig (2001) outlined for the analysis of data. The process began with the first author reading all the transcripts several times, following which she identified preliminary themes. These were labeled and discussed across a series of meetings between the first two authors. Conceptually related themes were then clustered, providing a hierarchical structure, and finally, she produced a summary list of superordinate themes accompanied by a set of extracts illustrating each theme.

5.6 Analysis and Discussion

5.6.1 Deservingness

As the “gift of life,” many construe a transplanted organ to be the ultimate gift. All those involved in the transplantation process widely acknowledge the paucity of organs available for transplantation, and many participants reported experiencing angst about
receiving a rare and precious donated heart. They spoke of their struggle with the issue of deservingness. Many participants sought to establish that failure of their own heart was the result of circumstances outside their control and occurred despite their conscientious attention to health and fitness. For example, Ruth stated,

I never had a chronic illness, um, and I was always really fit and well and . . . I got a virus and I um, which completely trashed my heart as it turns out. . . . Before I had that virus I was riding probably ten kilometers to and from the local swimming pool and teaching swimming all day. So I’ve always been quite fit, never smoked and didn’t drink to excess. . . . I’ve never been really sick in my life.

Ruth distanced herself from any blame in relation to her “trashed” heart. She recounted her active and healthy lifestyle to highlight that her damaged heart was the result of unfortunate circumstances rather than any wrongdoing on her part, and through this negation of blame, she attempted to demonstrate that she was worthy of receiving a second chance.

Demonstration of deservingness was also a concern for Diana, who similarly contracted a virus that damaged her heart. Whereas Ruth’s rationale centered on her healthy lifestyle and previous good health, Diana’s was based on establishing that she was a “good bet”:

You have every conceivable test. Kidneys, osteo [tests for bone health], everything, your brain, you know, whether you’re ah [pause] fit enough to receive a heart. . . . You have to pass your tests. Like you can’t just go in because your body has to be strong enough to handle it. . . . And when all the results come in
from your collection, you um, are told whether you pass to go on the list. . . . I got through. Yes, my body was strong enough. . . . Because it’s not worth giving you a heart if you can’t, if you can’t cope with it.

For Diana, worthiness meant having an able body, a body that could “cope with it.” From within this framework, the body is objectified; it becomes a machine of sorts, and before a “broken” part can be replaced, the relevant personnel need to make sure that everything else is in good working order. There is a sense of justification in the preceding extract. Diana conveyed her thinking that it is right to be tested, that this is a necessary and objective way of determining who should, or should not, receive a heart.

Diana revisited the concept of deservingness several times throughout the interview. It became evident that many years posttransplant, this was still something of concern for her, especially in relation to others who did not receive the needed heart. She was on the transplant waitlist for more than a year:

Yes, in that time we are tested every, every so often, you know. You have to go to the gym three times a week. . . . Um, a lot of the guys didn’t receive hearts. Um, some of them um, like were just waiting really, there, not ever going to get one, you know what I mean? That was the sad part. But ah, sometimes you’d be exercising, you’d feel sick and dizzy and you’d be on the floor, on a bed, you’d be there.

The sense of a form of unwanted competition with other patients on the waiting list, although unarticulated, is clearly present in this extract. Diana was aware of many others on the waitlist who had missed out and seemed concerned to continually demonstrate that
she deserved to receive a transplant. She emphasized the point that regardless of how ill she felt, she went to the gym and did what (she felt) had to be done. Diana’s concerns about establishing her deservingness resonate with Douglas’s (1992) observations about visible gift exchanges, which she argued are “readily subject to public scrutiny and judgments of fairness” (p. 162). Ruth’s and Diana’s narratives demonstrated a keen awareness of this, as did those of Colin and Jeffrey, which follow.

Colin experienced many years of heart problems before receiving a transplant. He reported that he did some “detective work” postsurgery and, based on news reports and a comment the doctor made about the size of the heart, is “99% sure” that his heart came from a young woman. Colin spoke at length about this (hypothetical) woman’s family, most particularly, what they might think of him (i.e., an older man) receiving the heart of their loved one. As he spoke, it became apparent that perceived worthiness in the eyes of the donor family remained a concern for him:

As I’ve mentioned before, I do feel guilty [laughs nervously]. Guilty? I’m not sure what the right word is. I, I haven’t plucked up the courage to, to write to [the donor family]. [Sighs deeply.] I suppose I’m a bit dubious the fact they'll think: “Ah, it's gone to an old fart that [pause], instead of going to some young person that has got his life ahead of him.” Um, whereas me, I’ve only got a few years. [Long pause.] But there wasn't anybody else who could have accepted it at that time, I suppose. A younger person. But I, yeah, now and, every now and again I do start thinking of it, especially anniversary time.

Colin questioned whether he deserved to receive a “young” heart. His guilt, and consequent lack of contact with the donor family, appeared to be associated with a sense
of shame. He feared he might not measure up and was worried that the donor family might think the heart of their loved one was wasted on an “old fart,” and he managed the (assumed) questions about his deservingness by suggesting that he was possibly the only person to whom the heart could have been given at that time.

Jeffrey’s experience was similar to Colin’s in that he, too, expressed concern about the judgments that might be made on the basis of his age:

It was a happy-sad occasion. Ah, I felt I was too old for it because I was nearly [age] then and I thought, the heart for me. I knew they always put a young heart in a person, would be wasted on someone who’s had a life. So I told doctor. I said: “Instead of wasting it on me, put it in someone young,” and he said: “No we don’t look at it that way. We look at it as a person. You are fit. You may be fitter than a lot of younger people and we don’t look at it that way.” So, he recommended: “It’s up to you if you want it.” And Dr [Name] did the operation. He checked me out and said I was a perfect candidate for it because all my other organs were perfect. They didn’t find anything wrong and that was for good living I think. I never drank much. I would drink now and again. Never smoked at all, and ah, lived a clean life.

Jeffrey, like Ruth, justified the receipt of a new heart by highlighting his “good living” and “clean life” prior to the onset of his heart disease. Of particular interest is the way in which he recruited the doctor’s voice into his narrative; it is not he, himself, saying that he deserved the heart but rather “the doctor” (objective and unbiased) who made the judgment that Jeffrey was a better candidate for the heart than other, younger candidates. Although in the preceding narrative, Jeffrey suggests that he might have reconciled the
issue of worthiness in his own mind, like Colin, he expressed concerns about how the donor family would feel if they knew about him:

I keep in contact with them by sending messages through the [Organization]. So that, just tell them that I’m doing alright... I prefer it like this. Um, they don’t know, they probably, if it’s a young person’s heart they’ll say: “An old guy!” Ah, there may be some, ah, discrimination, or sad feeling, or [pause]. [I’m] happy for it to be like this... Just let it be.

For Jeffrey, the preferred course of action was to remain demographically unidentified to the donor family so they would not (apparently inevitably) be disappointed by the realization that he is an “old guy” and, as such, a less deserving recipient of their loved one’s heart than someone younger.

Colin and Jeffrey’s concern that they would be considered less deserving recipients of a donated heart than a younger candidate is not unfounded. Research has indicated that, as far as the lay community is concerned, age should be a relevant consideration in determining who receives donated organs. Browning and Thomas (2001) investigated values and preferences about organ allocation in a community sample and found that priority rankings were most influenced by recipient age and prognosis. Although over 90% of participants believed that recipient sex, socioeconomic status, employment status, and occupation should not inform allocation decisions, 65% believed that young people should be given priority over older people. Sharp (1995) reported that receiving a transplant might, in and of itself, influence recipients’ assessments of their own social worth. Although the greater value attached to providing life-saving treatments
for younger people might be understandable, it is important to realize how this can contribute to an emotional burden of undeservingness for some older recipients.

Sothern and Dickinson (2011) stated that the scarcity of available organs underpins transplantation policy and media coverage and, by virtue of this, the organ recipient cannot be passive in terms of his or her relationship with the community from which such a “gift” has been drawn. Instead, recipients “must carefully construct their posttransplant life to ensure that these rare gifts are not wasted” (p. 891). Many participants in this study emphasized their understanding of this obligation and stressed the responsibility they felt to look after their new hearts. Jess, for example, spoke very briefly of what led to her need for a heart transplant and of the transplant surgery itself, and reported that her life posttransplant has not been without challenges. Jess became most animated when talking about the way in which life posttransplant “should” be lived. Speaking of the donor family, she said, “They’ve given me a gift so I can now live my life.” She then stated,

It’s a second chance of life. . . . Now, without the transplant, you wouldn’t be here. So, it is classed as, you’ve been given a second chance of life. Like, I mean, you’ve been given a second chance of life, I’m sorry, you take it and you do the right thing. So . . . watching what you eat. Um, like make sure you take your tablets when you’re supposed to take them. Not run out of your tablets. Make sure you keep your exercise up.

At two other times during the interview, Jess returned (unprompted) to the topic of caring for her heart, and each time she stressed, again, that she was doing “the right thing” (i.e., being responsible and taking the best possible care of her heart). Jess’s narrative reflected
the pressure she felt to be “the good organ recipient,” showing the transplant community that her gifted heart had not been wasted. As Sothern and Dickinson argued, this duty of care that recipients take on performs the dual function of demonstrating worthiness and also reciprocating for the precious gift received.

Karl’s story was noteworthy in that he was the only participant who did not address the issue of deservingness. He told of his transplantation experience in a matter-of-fact manner: He became ill, he sought help, his doctors offered a heart transplant as treatment, and he accepted it. Acceptance was a key feature of his narrative; it was woven throughout his story from the initial description of his illness to the present time, several years posttransplant. Of his time on the waitlist, he said,

I was, sort of pretty sick and that, you know, but I was, I was getting on with things, you know. Just waiting, waiting for it to happen. . . . Wasn’t worried. Well if it doesn’t arrive, if it doesn’t get here on time, that’s part of life. If it happens, it happens. If it doesn’t, yeah, it’s just one of them things.

Among the participants, only Karl gave no indication that issues of deservingness were raised for him at any stage of his transplant experience: an unflinching acceptance of his life “as it was” seemed to negate any such concern on his part. However, he described his own “acceptance” as so unusual that it prompted special attention from the medical staff:

[The psychologist] comes to talk to you about, you know, how you’re feeling and that and, the person they sent, I must have spun her out because her boss came in the following day, to check up to make sure, that she got it [right] [laughs]. Yeah, coz apparently I, [laughs] I surprised everyone, you know, by, by me outlook and
that... [By being so] normal, you know, just accept, accepting everything as it was going on... [They thought it was] weird.

From the perspective of the transplant team, viable organs are a scarce, socially valuable resource (Sharp, 1995). Members of this team are considered to be “gatekeepers” who, acting on behalf of the wider community, guard this resource vigilantly and ultimately decide (via a biological, psychological, and sociological screening process) who is, or is not, worthy of receiving “the gift” (Fox & Swazey, 2002). Karl’s reporting of events provided evidence of gatekeeping in action (i.e., his “normal” acceptance of what was transpiring in his life warranted a visit from a more senior psychologist to “check up” on him). It was Karl’s failure to show an appropriate level of awe at the prospect of a new heart that seemed to mark him out as unusual. The surprise and concern at Karl’s nonperformance of the expected “good prospective recipient” role (Sothern & Dickinson, 2011) provides some sense of the normative expectation that organ recipients will demonstrate awareness and gratitude for their good fortune and be at pains to reassure others that they deserve the life-changing donation they are receiving.

5.6.2 Nuances of gratitude

Social discourses in relation to transplantation tend to focus on the magnitude of the gift; it is a remedy for all the recipient’s ills. However, in contrast to popular opinion, research has found that although we have seen remarkable improvements in functional outcomes, the immunosuppressant drugs taken to avert rejection are implicated in the development of a wide range of diseases and disorders (Hosenpud et al., 1999; Jiang et al., 2010). In addition to the physiological implications of transplantation, extended periods of illness
and recovery can place a strain on personal support systems and economic resources. Life posttransplant is not without complications, and although some participants embraced the issue of gratitude wholeheartedly, broaching the topic without prompting and giving detailed descriptions of to whom and for what they were grateful, others were more tentative in their approach and were relatively vague about what they were grateful for (e.g., “Oh, for everything”). The following extracts suggest that there is not necessarily a direct trajectory from receipt of a gift (even one as precious as a heart) to unmitigated gratitude.

Diana, for example, raised the issue of gratitude early in the interview:

I know that I’m very blessed to have a heart. . . . It’s perfect. . . . I’m very grateful for my heart. I’m grateful for everything. I’m grateful for [Hospital]. Ah, the institution is wonderful. Yeah. And for my family. Yeah. Christmas and birthdays and celebrations. . . . That’s what I’m grateful for. Yes. The celebrations.

Later, while talking about gratitude, Diana returned to her time on the waitlist. She recounted a ghoulish interest in car accidents (and anticipation of opportunities they might offer):

After [a while] you realize somebody has to die, and that was the hard part . . . thinking that somebody has to die so you can have their heart and, then, you go the other way where you think: “Oh beauty.” It’s an awful thing to say but you think: “Oh there’s an accident [laughs nervously] . . . I hope they can go on life support.” And it’s an awful feeling, to be saying that, but every time there is an accident I think like that. That somebody might be able to live after death, you know.
In relation to the preceding extract, she described how fortunate she felt to have received a “good” heart:

[The doctor] said when you’ve got that sort of injury, a brain injury, there’s no hope of recovery, and that’s when the support system is, is ah, turned off, and you um. Then it takes so many hours to harvest the organ, and they’re the best ones to get [laughs nervously]. You know, ones that have come off life support. I was lucky to have one like that.

She spoke of her gratitude to the donor and donor family:

Ah, I’m very grateful for my heart. And my donor. Ah, without them I would not be here. . . . Yeah, I think about it sometimes. I think mainly about her family . . . how they cope with Christmas and her birthday and things like that. That wanders through your mind at Christmas and Easter and times like that. . . . Because they’ve lost her. Um, no. But then again, on the other hand, you balance it out and you’re grateful for what you’ve got. Very grateful.

Over the course of the interview, Diana dared to discuss topics rarely broached. She acknowledged the negative aspects of transplantation and reported the conflicts they evoked for her: the difficulty of dealing with the knowledge that someone “ha[d] to die” for a heart to become available for her and the excitement of hearing about traffic accidents and the opportunity they might offer; not wanting to hope for someone else’s death, while also hoping for exactly that; wishing for one of “the best ones”; and finally, receiving the good news that a heart had become available, knowing that someone else had just received devastating news.
Diana adopted a tell-all approach to her story, and the inclusion of her “darker” thoughts and feelings served to illustrate that the source of her gratitude (i.e., her new heart) was also the source of shame, guilt, and sadness. She expressed gratitude throughout the interview: At times this was unrestrained and joyful, at other times it was reserved and pensive. The preceding extracts suggest that, as a lived experience, gratitude is finely nuanced, tempered by the complexity of the contexts in which it occurs as well as the coexistence of other emotions.

Cecelia reported that her transplant surgery had not proceeded smoothly and that she had to endure much more than is generally expected in terms of follow-up treatment. Throughout the reporting of her transplant experience, Cecelia oscillated between gratitude for the fact that she is “still alive” and sadness for the many ways in which her new heart has not met her expectations:

There’s some type of reverence there. Yeah, some type of reverence . . . as if, um, I don’t, don’t know how to explain it. . . . [It’s] certainly not associated with happiness and certainly not a, complete sadness. . . . I guess it, it’s acceptance. Yes. Yeah but it, it’s more than acceptance. It’s um, there’s a gratefulness there but there’s also a type of holiness that goes with it all.

Cecelia reported that she was grateful to the transplant team, the doctors, friends, the family that helped to look after her daughter, and the donor family. However, she emphasized the negative as much as the positive in her narrative. In the first interview, she recalled that she had had “such a rough time . . . and was really, really sick afterwards,” and she went on to speak of the side effects associated with antirejection medication:
I think the tablets waste, cause muscle wastage. They’re strong and . . . well I feel as though I, th, they poison your body. I think they do. You can feel it. Poison all out, throughout your body, I think. Well I think you can. But the doctors just say: “Well, that’s life.” [Laughs nervously]. You know. Get on with it [laughs again]. They are sympathetic but what can they do about it, you know. You’re stuck between a hard place and a rock really.

In the follow-up interview, Cecelia reported that her experience was markedly different to that of others she knew who were “at the gym bouncing around like jellybeans” 2 or 3 weeks after leaving the hospital. Instead, she was improving “in really, really, really slight increments.” To add to this, she stated that a problem had developed with her new heart, which might lead to the need for additional treatment in the future. Cecelia indicated that she had become disillusioned by the slow pace of recovery and ongoing health issues. When the interviewer asked if there were ways in which her transplant had not met her expectations, she replied, “Certainly are [laughs]. Most ways, I think. Mmm.” She then went on to state,

No, the heart hasn’t [made her feel like her “normal old self”]. Not at all. That’s fine. That’s just the way my life’s supposed to go I guess. Um, I star, started a letter to the donor family . . . but I’m not really in the mood to finish that either because I don’t want to be cynical about it because I’m really very grateful. Um, yeah until I feel a little, a slightly little bit better, I probably won’t finish that letter.
Cecelia’s narrative indicates that she felt cheated by her transplant experience and that, like Diana, her experiences of gratitude have been moderated by a highly complex interplay of emotions. In some contexts, Cecelia’s experience of gratitude was molded by the “reverence,” “acceptance,” and “holiness” she felt in relation to her new heart. In others, her experience was shaped by the reality of her ongoing health issues and the sad acceptance of the high costs involved in keeping her new heart beating.

All participants spoke, to varying degrees, of the impact of immunosuppressant medication on their current health (e.g., digestive complaints, weight gain, skin irritations, tiredness, degeneration of muscle and bone, and problems with the “new” heart). John, like many, stated that he now has to be “vigilant” in relation to health and diet:

I mean, eating in itself is a survival technique because your diet is so drastically changed now. Ah, there’s things you’ve got to watch out for, stuff you can’t eat, stuff you shouldn’t eat. . . . You eat like a pregnant woman. Listeria! E. coli! I would probably be worse off [than a pregnant woman], obviously because of a suppressed immune system.

The narratives of some participants alluded to the exchange of one set of issues for another. This is not unusual for organ recipients: Crowley-Matoka (2005) utilized the term persistent liminality to describe the posttransplant state of flux, in which understandings of sickness, health, and normality must be constantly (re)negotiated. The lived experience of transplantation often lays bare a “deeply-vexed version of the ‘gift of life’” (Crowley-Matoka, 2005, p. 822).

The desire to talk about the ways in which the receipt of a donated heart still left the recipient with substantial ongoing health issues was common across the interviews.
Although limitations of the transplanted heart, in terms of both quality of life and life expectancy, are salient for participants and inform the lived experience of transplantation, they are largely missing from lay social discourses of organ donation. Previous researchers have discussed this disjunction between the dominant (gift of life) discourse and the reality of receiving and living with a transplanted organ (Shaw, Bell, & Webb, 2012), and Shaw (2010) questioned the underlying ethics of adopting or utilizing language that does not accurately reflect the phenomenon one has appropriated it to represent.

Most participants who mentioned negative aspects of their experiences appeared to feel guilty for doing so. They spoke apologetically of their complaints, highlighting a potential struggle for many recipients. On receiving the gift, they enter into a social contract (Mauss, 1970), and the community expects that they should be grateful. Heart recipients are aware of the value of the donated heart; they, too, believe they should be grateful. However, transplantation can be psychologically hazardous, with symptoms of distress experienced for many years postsurgery (Dew et al., 2005; Rainer, Thompson, & Lambros, 2010; Triffaux et al., 2001). This might be attributed, in part, to concerns arising from the limitations of the gift and the persistently liminal roles (i.e., sick–healthy, patient–normal person) recipients occupy (Crowley-Matoka, 2005). The lack of available social discourse in which to locate these experiences, discourse that can integrate both deep gratitude and ongoing struggle, can make it difficult for transplant recipients to articulate and have acknowledged their full range of experiences.

The source of gratitude in the transplantation experience (i.e., a new heart) might also be the source of a vast array of other emotions (e.g., joy, hope, anxiety, guilt, shame,
and/or obligation). The interpretation of any given emotion depends on the entire context within which it is experienced. Diana, for example, expressed gratitude for all the changes that had taken place in her life as a result of her new heart. The valence of her gratitude experience in this context was highly positive, charged with joy and hope. She also expressed gratitude to the donor and donor family. The valence of this gratitude experience tended toward the negative, charged with sadness and shame (i.e., in relation to her “wish” for an accident to occur and to receive the heart from a brain-injured donor). The current data set indicates that experiences of gratitude differ across various contexts, and these differences are not restricted to the intensity of gratitude (i.e., more or less) recipients experience. Gratitude is undoubtedly a positive emotion, but the lived experience of this emotion might be less than strictly so.

5.6.3 Giving forward

Reciprocation in response to a donation is not welcomed (Douglas, 1992). However, Siminoff and Chillag (1999) warned of ominous implications for social order and cohesion if recipients do not repay in some form the debt of transplant. Most participants in this study had not attempted to “give back” directly; only two had made contact with the donor family by writing letters to express their gratitude. This does not mean they did not experience gratitude or the compulsion to make a return on the benefit received. Shaw (2012) found this to be the case, also, in her study of reciprocity within the New Zealand organ donation system: Recipients anguished over letter-writing to the donor family; many experienced guilt and/or anxiety if they were unable to do so; and letter-writing (for those who were able to do this) did not necessarily ease the burden of the unpaid debt. The solution to the reciprocity dilemma, for many participants in the present study, was to
“give forward” by offering their support to others, thereby satisfying the terms of the social contract and their own need to repay.

Many participants joined support groups as a means of helping others. Colin, for example, spoke of such a group and reported his frustration at the attempts of hospital staff to thwart his efforts to do more:

This privacy thing, they don’t like letting patients talk to other patients too much unless they instigate the thing. We were heavily involved in a support group but you got no help from the hospital in telling us there were patients around that could do with some help, and that we found very disappointing. . . . I mean it’s a privilege to have it done. Why not tell other people about it? . . . We put a brochure up, but people didn’t avail themselves of it because it wasn’t pushed by the girls there. . . . That, that would be the only failing I would put on the hospital.

Another way in which heart recipients attempted to give forward was to become pro-donation advocates. John, for example, reported his frustration at what he believed was a general apathy in the community and outlined a potential solution to this particular problem:

I don’t think the media have any idea. . . . [In the hospital] I wrote pages of advertisements for [Organization] and all those sorts of things. Looked out for stories in hospital. . . . I don’t, I can try to get people to appreciate what it is. But they do that just by seeing me and by seeing other transplant patients as well. . . . I think they should show a little more of the people who have received this gift, um, and center on just getting people on donation. Getting them on to the register. That’s the most important thing.
John, like many of the participants in this study, acknowledged an acute awareness of the scarcity of hearts available for transplantation. He spoke of his wish that as many others as possible receive the type of help he received. His frustration was patent as he spoke of time being “wasted” and his desire to promote himself, and other heart recipients, as living examples of what can be achieved as a consequence of receiving a transplant. Throughout his narrative he emphasized his wish to advocate on behalf of current and future patients on the waitlist. He hoped to give back by giving forward and argued that if people could “just see” how well he and other recipients were doing, they might be more inclined to place their names on the donation registry, thereby helping to alleviate the scarcity problem.

Richard had had a long history of heart-related illness and “had a feeling” there had been some “contention” among doctors as to whether he should receive a new heart because his body was in a “fairly poor state at that stage and it was a scarce resource.” Like John, he was also keenly aware of the organ shortage, and he, too, wished to advocate on behalf of those on the waitlist. He stated, as did many participants, that the family should not have the right to veto the donor’s expressed wish to donate his or her organs (as this reduced the potential pool of available organs):

   The donor apparently had . . . made his wishes known, but the family, as you are probably well aware, the family can override it, which I think is wrong. I think if, if the person, you know, if you’ve made a decision that that’s what you want to happen with your bits and pieces after you’ve gone, um, that should be respected. . . I just wish in many respects that, that there, that it would have more media
exposure than it does. . . . Most people still aren’t aware [that the donor family can override the donor’s wishes].

Many participants understood the support they offered to the transplantation community to be the means by which others could achieve a more positive transplant experience. Giving forward in this way is a form of purposive gratitude. Wood, Joseph, and Linley (2007) found that gratitude is related to the utilization of positive coping strategies (i.e., positive reinterpretation, active coping, and planning), and Wood, Maltby, Gillett, Linley, and Joseph (2008) found that gratitude leads to increased social functioning and decreased levels of stress and depression during a life transition. Gratitude results in particular actions (e.g., joining or initiating support groups) that can lead to an increase in self-efficacy, which in turn has the potential to influence the long-term transplantation experience (e.g., the types of activities and environments in which recipients choose to become involved). Our findings support those of Wood and colleagues in highlighting the role that gratitude plays in resiliency, coping, and well-being and indicate a need for the study of gratitude interventions in the context of transplantation.

5.7 Conclusions

Many accounts of transplantation allude to a rebirth or second chance at life for the recipient (Evangelista, Doering, & Dracup, 2003; Jones & Egan, 2008; Joralemon, 1995). Although transplantation might achieve good functional outcomes, the heart recipient’s “new” life might also be replete with many additional layers of psychological complexity. We sought to gain a better understanding of the lived experience of heart recipients in
Western Australia and to explore the experience of gratitude within the transplantation context. We provide new insights that extend the work of others who have conducted research in the field of transplantation (e.g., Shaw, 2010, 2012; Shaw et al., 2012; Sothern & Dickinson, 2011).

The most important of these insights concerns the understanding of gratitude in the heart transplantation context. The highly complex nature of gratitude is revealed through recipients’ ongoing struggle; the experience of gratitude is shaped by the highly intricate interplay of the consequences (both positive and negative) of transplantation and the other emotions (e.g., hope, joy, disappointment, shame, and/or guilt) evoked by this treatment and its outcomes. Successful transplantation involves more than a donated organ “working” in its new body; it also includes the emotional quality of the life that is extended by it. We offer insight also into how differences in the construction of the transplanted organ (i.e., organ-as-gift and organ-as-donation), although subtle, have the potential for profound implications with regard to long-term outcomes for recipients. These differences influence recipients’ understandings of their transplant experiences (e.g., the need, if any, to reciprocate and what an appropriate form of reciprocation might be) and, by virtue of this, the success of the transplant.

The powerful gift-of-life rhetoric that is pervasive in both medical and lay understandings of transplantation clearly resonated with participants in some ways; they expressed appreciation and gratitude to their donors and donors’ families as well as endorsing the ideal that they should find a way to express their gratitude to these donors (although most participants in this study had not yet actually done so). However, the focus in social discourse on organs as gifts emphasizes the moral transaction between
donors and recipients but minimizes the complicated moral relations between recipients and other candidates who have not (and perhaps will not) receive donated hearts. This issue was a clear concern for many participants, who worked hard throughout the interviews to demonstrate their worthiness; they were at pains to emphasize the reasons society could consider them worthy of a donated heart or to show that there were no other suitable candidates for the particular hearts they had received.

The level of concern most participants had shown in this study revealed how vulnerable and uncertain they remain (for some, many years posttransplant). The issue of deservingness, marginalized by gift discourse, is central to social discourse around donations. Donations are given to “causes” deemed to be worthy (Morgan et al., 2008). Participants signaled their understanding that judgments of deservingness are made and that their own claims to a heart were assessed in relation to those of other potential recipients. The social discourse around receiving an organ creates emotional vulnerabilities in recipients that need to be recognized and responded to.

Heart recipients were familiar with the emotion of gratitude. However, their experiences of gratitude were nuanced by the confluence of other emotions and were not always entirely positive. Gratitude was sometimes lightened by the coexistence of joy and relief; sometimes deepened by feelings of reverence; and other times darkened by the presence of shame, guilt, or frustration. Members of the lay community might be forgiven for thinking that a “new” heart resolves all of the recipient’s problems and that he or she should be eternally and straightforwardly grateful. Although transplantation does treat end-stage heart failure, the ongoing immunosuppressant regimes required to sustain the new heart introduce a new set of health problems and constraints on activity that can
sometimes be difficult to manage. To be grateful under these circumstances is not necessarily easy.

One of the most important distinctions between organ-as-gift and organ-as-donation understandings of transplantation lies in the manner in which the debt might be cleared. In either case, the recipient has received a benefit of immense value and, in so doing, has entered into a social contract. Societal expectations, which individuals take on, result in what Komter (2004) described as “an imperative force” (p. 196), which undergirds gratitude and compels recipients to make a return on the benefit they have received. One does not give back directly to the giver in the context of a donation. However, it is acceptable for one to “give forward,” to help others.

Fredrickson (2004) emphasized the pro-social aspect of gratitude in her broaden and build theory. Those who are grateful do not necessarily reciprocate quid pro quo. Instead, they might look for creative ways in which their expression of gratitude, via reciprocative acts, can benefit others. In this study, participants seemed particularly concerned to express their gratitude by finding ways to help others in the transplant community, via participation in support groups and research and through advocacy designed to increase the number of organs available for transplantation. Reciprocation in this form could perhaps be more accurately described as “giving sideways,” as recipients’ narratives suggested a particular responsibility to these others rather than a general desire to “do good.”

This research was based on heart recipients who responded to an invitation to participate in research issued via the hospital at which they had received, and continued to receive, treatment. Even though we assured the participants of confidentiality, these
participants might have restricted the scope of their narratives. This recruitment method might have precluded the voices of others, with a different range of experiences, and future research would benefit from the inclusion of participants recruited via different means (e.g., media advertisements). Research in this field might also benefit from the inclusion of the often-silent voices of the organ recipients’ family members, particularly spouses. Some participants in the current study routinely referred to their transplant as a joint (i.e., “we”) experience, in which their husbands or wives were included in all aspects of the experience bar the actual surgery. Future research might explore the extent to which these “involved others” also take on joint responsibility for care of the new heart and management of the complex moral relations arising from the transfer of the organ.

One of our main aims in the current research was to explore the experience of gratitude in the context of transplantation. The field of gratitude research might benefit from research that explores experiences of gratitude in response to other life-saving treatments or situations. A comparative analysis of the similarities and differences in gratitude across a range of life-threatening experiences will broaden understandings of gratitude and its potential to influence outcomes (both psychological and physiological) for survivors.

Transplant recipients exist in a persistently liminal space (Crowley-Matoka, 2005), in which illness, health, and normality take on new meanings. In this context, gratitude might function as a mechanism of negotiation. It represents a form of value adding, a way in which recipients can emotionally reorient to what has been added to their lives because of transplantation rather than what has been lost. In this respect, gratitude plays a role in meaning making and, in so doing, might lead to better adjustment
(Park, 2010). Participants in this study did not shy away from the negative aspects of transplantation. However, many spoke about how they, and their lives, had changed for the better as a consequence of this major life experience. They reported being less materialistic, less inclined to “sweat the small stuff,” more focused on the present and being alive, more involved in their relationships, more aware of the help they had received and continued to receive, and more invested in helping others. Despite the tribulations of immunosuppressant regimes, each new day was seen to be “a bonus.” The results of this research indicate that gratitude contributes in no small measure to the sense of a life worth living that many heart recipients achieve.
CHAPTER SIX

“It’s not a miracle, it’s simply good medicine”: The lived experience of liver transplantation

6.0 Relationship of the paper to the thesis

The paper presented in this chapter is the second in a series of three exploring the experience of organ transplantation, and represents the findings of an exploration of the liver transplant experience. The magnitude of what is received in the context of organ transplantation is undergirded by gift-of-life discourse. My interpretative phenomenological analysis indicates that receiving the ‘gift-of-life’ under the gaze of healthism (and the assumed bad behaviour of those with end-stage liver disease) is an experience rife with contradictions. These contradictions are presented across the themes of the paper: challenged identity; the role of work in establishing a valuable identity; and some dissent toward the view that donated organs represent the gift-of-life. The implications of universally applying a generic (i.e., gift-of-life) model of transplantation are highlighted and discussed.

The paper, titled “It’s not a miracle, it’s simply good medicine”: The lived experience of liver transplantation, is currently under review in Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine.
6.1 Abstract

Organ transplantation is the treatment of choice for end-stage liver disease, and its lifesaving potential is promoted via gift-of-life discourse. However, the general public can be critical of those with alcohol-related liver disease receiving scarce liver transplants, and gift rhetoric may have detrimental repercussions for those deemed (by themselves or others) to be unworthy of the gift-of-life. We explored the experience of liver transplantation via semi-structured interviews with 7 participants. Interpretative phenomenological analysis uncovered three themes: challenged identity; the role of work in establishing a valuable identity; and some dissent toward the view that donated organs represent the gift-of-life. We suggest the social stigma surrounding liver disease means that experiences of liver transplantation may sit uneasily with gift narrative, and a gift-of-life understanding of transplantation cannot be universally applied across the range of organs available for transplant.
6.2 Introduction

“Public asked to dig deep for dying addict” (O’Leary, 2010).

In 2010, the family of 25 year-old Perth woman, Claire Murray, was granted a $258,000 interest-free loan from the Western Australian government so that she could undergo a live liver transplant, to be performed in Singapore. This case sparked public outcry, as Ms Murray had previously undergone a publicly funded liver transplant that had failed, allegedly because she returned to her former use of heroin. As one report outlined:

[T]his case has posed a moral dilemma and polarised the community. . . . There are people who don’t believe Ms Murray deserves a second chance because she lost her first transplanted organ through drug abuse. . . . There is a legitimate rationale to this argument, albeit an uncharitable, some would say unchristian, one. (Weir, 2010)

This case highlights the centrality of deservingness to public understandings of organ donation. Ms Murray’s acknowledgment of her heroin use and its role in the failure of her first transplant brought these issues into unusually sharp focus, but the widely acknowledged association between liver failure and alcohol and/or drug abuse makes it likely that many people who need a transplant following liver failure will be subjected to assumptions and judgments about their own potential contribution to their predicament more than other organ recipients. In the current study, we examined recipients’ experiences of liver transplantation to better understand how the western social discourses surrounding both liver failure and organ transplantation shape those experiences.
6.3 Context of liver transplantation

There is widespread concern about the distribution of publicly-funded healthcare (Olsen, Richardson, Dolan & Menzel, 2003), and there is extensive research on public attitudes toward health expenditure (e.g., Robinson, Williams, Dickinson, Freeman, & Rumbold, 2012). The chasm between individuals’ expectations regarding their healthcare ‘rights’ and governments’ understandings of their healthcare ‘responsibilities’ is widening (Hill, 1996). The attributed cause of ill health is one of the primary factors considered in determining the fair and equitable distribution of resources (Hyde & White, 2010).

‘Healthism’ refers to the moralisation of health in Western societies since the 1970s (Crawford, 2006). Healthism assumes that individuals are largely responsible and accountable for their health status. A close connection is drawn between individual behavioural ‘choices’ and health outcomes, and individuals who experience ill health are thus seen to have failed to engage in responsible self-management. Concerns have been raised about the attribution of individual morality and culpability from health status (Yoder, 2002). Cheek (2008) noted the intense focus on ‘health as an ideal’ and ‘ideal health’ that exists within the ideology of healthism, and the use of language that denotes transgression (e.g., sin, bad, weak) when one fails to live up to this ideal. She argued that health has become a civic duty; and good health is seen to be “… a badge of honor by which we can claim to be responsible and worthy as both citizens and individuals” (p. 974). Galvin (2002) posited that understanding good health as the consequence of making the ‘right’ choices slides easily into blaming individuals for ill-health and can be “devastating” (p. 110) for the chronically ill, leading to guilt and self-recrimination.
Regarding liver transplantation, the public appears particularly judgemental and willing to discriminate against those who are considered to be responsible for their illness (Neuberger et al., 1998). In a scenario-based study of public preferences in the allocation of donated livers for transplant, most participants agreed that preference should be given to those with naturally occurring liver disease before those with alcoholic liver disease (Ratcliffe, 2000). Another scenario-based study found 35% of participants allocated no donated livers to patients with alcohol-induced liver disease, and a further 36% of participants allocated fewer donated livers to patients with alcohol-induced, rather than inherited liver disease (Wittenberg, Goldie, Fischoff, & Graham, 2003; see also Ubel et al., 2001). These findings in specific relation to liver transplantation reflect more general principles in the allocation of scarce resources, in which people judged ‘irresponsible’ arouse less pity and sympathy, more disgust and distaste, and are considered less deserving of scarce healthcare resources than those with uncontrollable and/or external causes of need for help (Skitka & Tetlock, 1992).

The point here is not to debate the legitimacy or morality of the judgments made, but to emphasise that such judgments are made, with implications for the transplantation experience of those assumed to be responsible for their illness. We posit that liver recipients might be more frequently targeted by a suspicion of ‘bad’ (antisocial/unhealthy/unworthy) behaviour than recipients of other organs, and such judgements of ‘undeservingness’ will have significant consequences for the psychosocial outcomes of transplantation.
6.4 Gratitude, deservingness, and shame

The normative expectation of gratitude is central to gift-of-life discourse, which informs the experience of transplantation (Shaw, 2012). However, the belief that one does not deserve, or is seen by others not to deserve, the ‘gift’ might influence the experience of gratitude. In an earlier study, we (Authors, in press) found that heart recipients sought to establish their deservingness of a ‘new’ heart by attempting to negate any sense of blame for their illness and by reporting in detail leading a ‘good’ (i.e., healthy) lifestyle both pre-and post-transplant. The heart recipients’ understanding of their deservingness influenced the experience of transplantation, their experiences of gratitude, and how they attempted to reciprocate for the benefit received. We question what might happen if the recipient believes he/she is not worthy or that others believe he/she is not worthy?

It is not always easy to receive from others, particularly if one’s worthiness may be in dispute. Exline (2012) questioned the understanding that kind acts will have uniformly positive effects, finding that some people on the receiving end of kindness perceived themselves diminished and shamed by the experience. Similarly, Exline, Lisan, and Lisan (2012) found that, although participants reported gratitude in response to kind acts, the majority also reported some shame, weakness or guilt. Furthermore, participants were most likely to report feeling gratitude in response to normative acts of kindness than non-normative (i.e., ‘amazing’) kindness. People who received ‘amazing’ kindness from others tended to perceive the kindness as being undeserved, which was in turn linked with reports of shame/weakness and mistrust, rather than greater gratitude. Exline and colleagues suggested receiving gifts that are perceived as undeserved can be a mixed
blessing. Although one might expect such gifts to elicit greater gratitude, the ‘undeserving’ recipient is vulnerable to feelings of diminishment and shame.

People experiencing liver failure are vulnerable to shaming judgements under the gaze of healthism - the widespread assumption that alcohol or drug abuse contributes to most cases of liver failure positions those who experience it as having failed to control their behaviour and take responsible care of their body. Brown (2006) defined shame as a complex, self-referential emotion, a painful experience resulting from the belief that the self is flawed and is consequently unworthy of acceptance and belonging. Tangney, Niedenthal, Covert, and Barlow (1998) argued that shame involves a harsh and condemning negative evaluation of the global self. Shame has been associated with the tendency to hide, motivating denial and withdrawal as the person attempts to escape the shame-inducing event and the implications of his/her behaviour (Sheikh & Janoff-Bulman, 2010). It has also been associated with intense anger, hostility and the blaming of others for one’s plight (Tangney, Stuewig & Mashek, 2007). Randles and Tracy (2013) found (in a sample of recovering alcoholics) that shame predicted the tendency to relapse, severity of the relapse, and declines in both physical and psychological health.

Our aim in this research was to explore the experiences of liver transplant recipients. We were particularly interested in how participants negotiated issues around deservingness, given the widely acknowledged shortage of livers available for transplantation and the widespread public association of end-stage liver failure with alcohol and/or drug abuse. We also sought to explore participants’ emotional experiences, particularly of gratitude and shame, in relation to their transplant.
6.5 Method

6.5.1 Participants

The participants were six liver recipients (five of whom were male), and one prospective liver recipient (a woman who was on the transplant waitlist). One of the participants had received two liver transplants, and one had received one liver transplant and was on the waitlist for a second. Ages ranged from 51 to 69 years ($M = 60.57$), and time since transplant ranged from 3 to 11 years ($M = 5.33$). Data came from semi-structured interviews, and all interviews were recorded and transcribed. Interview length ranged from 45 minutes to 2 hours and 15 minutes. We assigned pseudonyms to participants, and altered or omitted any potentially identifying details. This article is based on data drawn from a wider study investigating experiences of liver, heart and kidney transplantation.

6.5.2 Ethics

(Redacted) Human Research Ethics Committee granted ethics approval, as did the ethics committee of the hospital in Western Australia from which participants were recruited. A nurse practitioner, employed by the hospital, provided a list of patients (drawn from the waitlist and recipient list) who she believed to be healthy enough to participate in an interview. The first author mailed a participant information sheet (PIS) and an invitation to participate to all those on the list provided. Interested participants contacted the first author to set up an interview to be conducted at a location chosen by the participant (i.e., his/her home, the hospital, or the university).

Each participant signed a consent form at the beginning of the interview. With a view to providing support in the case of adverse effects, at the end of the interview we provided each participant with a card detailing a range of support options (i.e., contact
details of: the interviewer; support services at the hospital; psychology clinic at the university; and agencies that provided 24 hours a day/7 days a week telephone counselling). The interviewer telephoned each participant, the day after the interview, to check on his/her emotional state, and enquire if any support was needed. None of the participants reported adverse effects and, instead, many spoke of their gratitude for the opportunity to talk openly with the interviewer.

The first author conducted all interviews, which were aimed at gaining insight into the psychosocial experience of transplantation. As such, they targeted participants’ thoughts and feelings about various aspects of their experience (e.g., living on the waitlist; living with a transplanted liver, the changes that a transplant had brought about; general feelings of gratitude and/or indebtedness; the ways that transplantation is talked about in the media; and expectations for the future). The interviewer did not ask participants about alcohol consumption or drug use; however, all participants raised the topic at some point during the interview.

6.5.3 Approach to analysis

Interpretative phenomenological analysis (IPA) is particularly conducive to the exploration of the illness experience (Smith, 2011). As noted by Murphy, Dingwall, Greatbach, Parker, and Watson (1998), researchers need to be aware of their a priori assumptions, and how these might inform the collection of data and subsequent analysis. The first author, thus, kept a reflexive journal across the period of data gathering and analysis, in which she outlined her thoughts and emotional reactions to participants, their stories, and the transcribed texts. She noted how her thoughts and emotional responses changed as more data was collected, and over subsequent readings of the texts.
In the process of IPA, suggested by Willig (2001), the first author read the interview transcriptions several times and identified preliminary themes. The first two authors then discussed these themes across a series of meetings; themes were labelled, conceptually related themes were clustered in a hierarchical structure, and a summary list of superordinate themes (with illustrative extracts) was produced.

### 6.6 Analysis and discussion

#### 6.6.1 Challenged Identity

Scarcity is the reality of organ transplantation and the rare and precious nature of ‘the gift’ is widely appreciated. Media campaigns highlight scarcity with a view to increasing donation rates; scarcity is highlighted for the prospective recipient as he/she moves through the testing procedures to make it on to the transplant waitlist and then bides time on the list, waiting for an organ to become available; and transplant teams must make priority/allocation decisions as organs for transplant are not readily available for all those who need them. The scarcity issue underpins that of deservingness: if a person is seeking (or has received) a rare ‘gift’, one might anticipate that he/she would attempt to show deservingness for it. We found, however, that the male participants in the current study demonstrated a resistance to health discourse and to worthiness narratives more generally. Most openly acknowledged a pre-transplant lifestyle that incorporated practices not in keeping with social understandings of a 'healthy' (i.e., moral) life. Jack, for example, stated:

Drugs, drugs were certainly part of my life … not that I did that for long. But I did do it. So, um there’s no point in pretending I didn’t … I’ve always drunk too, all my life since coming of age or probably even a bit earlier than that … I was quite
a heavy drinker … I was drinking probably far, well, not probably, I was drinking far, far too much.

He later spoke of “20 years of sort of self-indulgence. Drinking and eating and living in five-star hotels with [the company] paying, um, you know. That was my life”.

Doug also spoke of alcohol and drug use: “I got into lots of trouble, um, and er, one thing lead to another, ended up [in trouble with the law], and um, drugs and all that sort of stuff, contracted Hep C”. He later said that he “…used to drink a fair bit. I wasn’t a clinical alcoholic though. Ah, I’ve changed. I was a bit of a dickhead, a drunk”. George reported that his doctor described his liver as being “shrivelled up like a dirty old orange” and, in relation to this, said that his (pre-transplant) lifestyle included “two main vices [a beer and a smoke]”, which he “absolutely loved”. Likewise, Rick described himself (pre-transplant) as “a drinker”. He went on to say he had lived in an environment in which “everyone drank”, and recalled his struggle to abstain from alcohol and the help he had received:

I was very fortunate throughout my waiting time and then my rehabilitation. Ah, there was [name], he sort of counselled me a lot because I’d been a pretty wild bloke, you know, and I, I was sort of wanting to get better, and thought: ‘Well, what’s life without doing what I’ve done all my life?’

The two female participants also brought up the topic of alcohol consumption, but in sharp contrast to the male participants, Joan and Lydia emphasised that their need for a liver transplant occurred despite their status as non-drinkers (both emphasised that their liver failure was the result of a disease/infection they had contracted). In reporting her
reaction when told she needed a liver transplant, Lydia highlighted her disbelief that someone ‘like her’ would experience liver failure:

I broke down and I cried and I, I was nasty to the doctors. I was nasty to everybody came near me. I, I, well you know, coz I, I just couldn’t believe it. Couldn’t believe it. You know, you walk down the shopping centre, you see these big people and there’s nothing wrong with them. And here I am, you know, ah, thinking, well I never drank, I never smoked.

In this extract Lydia contrasts herself with the stereotype of a person who might be expected to need a liver transplant. She dramatically emphasised the ‘unbelievability’ and, by implication, unfairness, of experiencing liver failure despite living cleanly.

Participants themselves often reinforced the view that overuse of alcohol and other drugs was typical of people who need liver transplants. Jack, for example, stated that:

[I]t’s quite difficult to get on the waitlist and that’s why a lot of people don’t get on it at all or die because, um, you know, people who have liver damage tend to be alcoholics, drug addicts, that sort of thing.

Despite reproducing this stereotype themselves in their discussions around liver transplantation, participants also appeared sensitive to “the public’s” judgement of them. Several times throughout his interview, Doug spoke about this issue:

With alcoholism, you know . . . Um, there’s a big, there’s a lot of stuff, judgmental stuff goes on about that, you know. That’s why there’s a six-month thing. You’ve gotta stay clean for six months to participate in the transplant
program. . . [The public ask] ‘Why are you wasting organs on eeeww?’ [grimaces].

He later spoke about his liver with respect to the gift-of-life:

That’s the thing, you know. Public, public perception of the gift is, is, yeah, you know, it’s good, but it’s those expectations: ‘You’re not perfect, you shouldn’t have that’ … So public perception; is it a gift? Yeah, yeah, I suppose they, they, they look at that, and that’s how they’ve been [pause] promoting it … Are, are you worthy of that gift?

The extracts above show the participants’ clear expectation that members of the general public are sceptical about the ‘worthiness’ of liver recipients. Liver recipients understand themselves as being stereotyped as “alcoholics, drug addicts, that sort of thing”, and recognise that those with alcohol-related liver disease (ARLD) are judged and found wanting (c.f., Thornton, 2009). We can see from these extracts how their need for a liver transplant constitutes a threat to their identity as moral and worthy members of society.

6.6.2 The role of work in establishing a valuable identity

One option for responding to the identity threat presented by the stigma attached to ARLD is to emphasise other valuable aspects of the self. For the male participants in this study, work seemed to hold this potential. Some spoke of their return to work with obvious relief and/or pride. Jack, for example, compared himself with others who went through the transplant program around the same time as he did. He reported that a “lot of
them had enormous financial problems and that to deal with” because they were unable to work, while he was “in the very fortunate position” of having worked for the same (“very supportive”) company for a long time. He went on to state he had been able to take extended sick leave “on full pay, and I’m very well paid, um, and a lot of people, you know, again as I said, a lot of them are, er, not necessarily in life’s best circumstances”.

George spoke of his swift return to work: “I was back at work within nine weeks, and you know, they say people don’t usually do that sort of stuff. But to me, that was nine weeks too long”. Anthony’s return to work was even quicker:

[T]o be honest I was back at work with, within two weeks of the operation, of coming out of hospital. Yeah. Before I was allowed to go back to work. I just went back to work. I never sought permission off the hospital. I could get up. I could go around and move about, went back to work.

Anthony raised the issue of work several times during his interview. He later stated he returned to work so quickly “to regain normality and, prove that I was ok and get back on board with life”, and again later he recalled he “wanted to get back to normality. Even if it hurt”. The importance of returning to work in these men’s accounts of their efforts to recover after their transplant suggests work is a key means of establishing productiveness and value to society. Their self-admitted excessive use of alcohol and other drugs made it difficult for these men to construct an identity as ‘worthy’ transplant recipients based on their history (unlike Lydia or Joan). However, by emphasizing their productive contributions as workers since their transplants, they were able to establish themselves as ‘worthy’ based on their subsequent efforts to make good, socially productive use of the opportunities provided by their transplant.
The crucial importance of work in establishing a valuable post-transplant identity is highlighted again in the struggles expressed by Doug, who (several years post-transplant) was still unable to work. He returned to the topics of work and his reliance on government support many times throughout his interview. At times he spoke with despair:

Coz by the time you get your transplant, a lot of people they’re that sick it’s, they haven’t been able to work, bills pile up, you know. You’re at the tail end of everything, and er, um, you get out of hospital and you try and get things going. I know it took me a long time to get over it all, and ah, trying to get any help out of the government, um, other than getting the pension, um, is, is so difficult, you know. . . . I really think that there should be a support network attached to transplant, for anyone, I think, that gets out of hospital after a major illness, and the government steps in and goes ‘Right, what can we help, how can we help to get you, ah, back to being ah, ah, ah, a good member of the community?’ You know, instead of, you know, just having to get pension all of the time.

At other times Doug was clearly angry about his current situation. He reported that through the process of being sick and unable to work, he and his wife had “lost the house” they owned, and had to rely on the government to provide them with “public housing”. He returned to despair:

I would like to go and get a job. I can’t do any [previous] work anymore. They reckon all my bones are shit. They do every test imaginable. Coz the drugs they give you deplete your calcium, magnesium. Well my bones are just about, when I get up in the morning, I creak, creak, creak . . . Yeah, I’d love to be able to do
something . . . I always worked. I always worked hard. I supported the family. . . .

I’ve gotta make sure [wife] is ok, you know. My days are numbered. I don’t know. I’m not going to see old age. Statistics tell me that. But ah, I’ve got to make sure that [wife] and [son] are fine, you know. That’s my aim in life, is to make sure they’re all right.

Sickness, weakness and reliance on others in society for financial support (as well as life itself) all come to the fore throughout the transplantation process. Doug’s story was one of ongoing struggle; several years post-transplant he was faced with deteriorating health, and diminishing prospects of being able to work and provide for his family. Doug expressed considerable anger, at times, during the interview and tended to blame others (particularly government support agencies) for his current circumstances. As discussed previously, shame has been linked with anger, hostility and externalizing of blame (Tangney, Stuewig, & Mashek, 2007). For Doug, we argue, this stems in part from the lack of available discourses in which he might express, and have acknowledged, the full scope of thoughts and emotions relating to his experience of transplantation.

The need to establish value to society through productive work (and the associated earning capacity) can be understood as a response to the shaming nature of public discourse around ARLD. Shame discourse undergirded the transplant experience of many liver recipients in this study. Being positioned within this shaming discourse, it might be difficult to believe one is truly deserving of the gift-of-life, and receiving a gift of such magnitude might serve to further exacerbate feelings of shame in a recurring shame-unworthiness cycle.
6.6.3 Some dissent toward the view that donated organs represent the gift-of-life

Gratitude is anticipated in response to a gift, by the giver, the recipient, and others. Participants in the present study were, without exception, grateful. Joan focused her gratitude on her transplant and donated liver. She was ‘certain’ she received a liver from a “young lad … one who’s had respect for his body through his life, his short life be it … so I respect mine … I think he’s led a clean and healthy life and I do the same”. There is an ‘explicit construction of care’ (Sothern & Dickinson, 2011) for a gifted organ, and it must be adhered to as a means of reciprocating for the gift-of-life. Care, Sothern & Dickinson argue, is a shared accomplishment, involving not only self-care (as care for the gifted organ), but also care for all those others involved in the biosocial community of transplantation (donors, other potential recipients, medical personnel), and finally, care of the gift-of-life metaphor. “Individuals are compelled to return the gift of the organ by living as the good recipient, because this is the promised outcome of the ‘gift of life’” (p. 899). Regarding ‘care’, Joan reported strictly adhering to a good post-transplant diet and regular exercise, as well as to her regimen of immunosuppressant medication and instructions given to her by medical staff: “Whatever the doctors have told me, I have done”. She spoke of much deliberation over the letter she wrote to the donor family, which came “from [her] heart”, and throughout the interview expressed considerable gratitude to the donor and donor family, and to the transplant team:

I am truly thankful to the young lad. Um, but to his family coz they made this possible for me … I’m, yes, I am grateful to them for [a great life], for, for what I’ve got. Um, It’s great to be here on earth still.
To the doctors and the nurses. They are great people, and they care for you a lot. Um, and it doesn’t matter how many years [have] passed, they still care about you. And it’s um, for them to see us the way we are, the satisfaction they must receive from it all.

Joan also spoke about her attempts to support others:

If I can put my story out to anybody or if I can assist other transplant patients get through their journey, I’ll be there. Coz I really want to give back what I’ve got. You know, I’ve got life. Um, I mean I go to clinic … [a]nd I think well, if I put a positive thing out there, if my positive energy can get to these people and they can sort of say well, you know, how come she’s like this? Why can’t I be like that?

Joan can be regarded as an exemplary ‘good recipient’. As previously mentioned, she contracted a disease that led to her liver failure (which is an ‘acceptable’ reason for support in the eyes of the community), and by virtue of the level of ‘care’ reported she showed an understanding that she deserved her donated liver. The circumstances of Joan’s illness allowed her to find a place for herself in the ‘deserving and grateful’ narrative, and her many expressions of gratitude in relation to her transplant reflect this. However, if one is coming from a place of shame, it is difficult to site oneself within this ‘deserving and grateful’ narrative. Fisher, Nadler, and Whitcher-Alagna (1982) reported on recipient response to aid and postulated that the receipt of help may not be a pleasant experience for those with internal attributions for failure. They outlined a ‘threat-to-self-esteem’ model of recipient response to aid: asking for help involves a public admission that one is ‘inferior’ and this experience might be self-threatening; (self) attributions of
unworthiness are highly threatening; and help which compromises values of self-reliance and independence might elicit negative/defensive reactions such as lowered self-concept and/or unfavourable evaluations of the donor and/or aid received. The narratives of many of the men in this study indicated that, for them, transplantation was a highly self-threatening experience and, as proposed in the model outlined above, this elicited defensive reactions that included some unfavourable evaluations of their experience. Attempts were made to discursively redefine the situation, lessening the value of the help received, and expressing gratitude in relation to aspects of life other than transplantation and/or the donated organ.

George, for example, received a liver several years ago and now needs a second transplant. He brushed over the topic of gratitude relatively early in the interview, stating that he was:

[G]rateful that someone’s donated their organs, that’s tremendous but, yeah, I just, I wrote a letter to the first, um, family. Never got a response, and (pause) which is fair enough, you know. They didn’t want to, carry on. They just, what was done was done, so (pause). Whether that’s what has, not ticked me off but given me this, like, sort of attitude. Like I wish some, hurry up, some bastard would die and give me their liver, type, sort of thing. That’s some of the things that I think of a lot.

George did not mention gratitude again until asked directly. He outlined a number of things he was grateful for (e.g., his grandchildren, “life in general”, travel with his wife, going to the pub with his mates - for a lemon squash) but did not mention any aspect of his transplant. The interview with George was dominated by a recount of his dealings
with “apprentice doctors” and his reliance on the transplant team, which he reported, for the most part, in negative terms.

When asked if there was anything in his life that he was particularly grateful or thankful for, Jack replied that he had a “relatively blessed life” even though he had “done nothing to deeply deserve it”. He spoke of a life of extensive travel, friends all over the world, about the fact that he got “paid extraordinarily well”, and that he had not lost any close family members. He did not mention his transplant. When asked directly if he experienced gratitude in relation to his transplant he paused and then replied:

Obviously, you know, it’s a very abstract thing. The, the donor sort of situation. Um, I’m supportive, um, you know, I always, sort of, write my cheques to the group and all that sort of stuff, but, um … some people have a certain amount of anxiety about who gave it or something. There never, er, has been an issue for me, you know. I’m eternally grateful obviously that someone, um, donated their liver. I never understand people who don’t put themselves on donor lists but that was long prior to me actually being, needing one.

He went on to say:

I don’t know whether gratitude’s quite the right word but ah, but I’m very conscious of my good fortune. Coz it, it had a much better, stronger chance of turning out much crappier.

Jack did not speak of gratitude again until asked if he considered his liver to be the gift-of-life. He responded:
A gift of life? Well I suppose, in bald terms, I, I suppose it is, yeah. But as I said, I fail to comprehend … I mean, it’s not like it’s ah, a particular miracle. It’s just where science is at, at the moment. If I’d got sick ten years earlier, I’d be dead, um, and, going back to your question of gratitude. Yes, the timing I’m grateful for because not too many years before that, transplants weren’t available, of that sort anyway, and um, it will move on, and ten years from now donors may not even be necessary. I mean that’s a very real possibility in medical science. Um, so I, I don’t think you can be over precious about it either. I mean, it’s not a miracle, it’s simply good medicine or, or a move, step forward.

As outlined above, Jack was not ungrateful; he spoke of being “blessed” and “fortunate” in many respects. However, when asked explicitly about gratitude in relation to his transplant and the gift-of-life, he responded he was “obviously” grateful, although he downplayed the generosity of the donor by expressing his (prior) expectation that everyone would “put themselves on donor lists”. Jack moved on in his story to discount the ‘value’ of his donated liver and transplant surgery: it is not “a particular miracle”, it is “just [emphasis added] where science is at”. He was grateful, not so much for his transplant, which is “simply good medicine”, but for the timing of his sickness (as the “science”, to help him, would not have been available ten years ago). As outlined previously, lowering the perceived value of the donated liver/transplant might be a means of managing a situation that is self-threatenng (Fisher et al., 1982).

Anthony, like George and Jack, downplayed the magnitude of ‘the gift’. When asked if he thought of his donated liver as the gift-of-life, he responded:
I think I was already alive before. I’ve been given an extension. Yeah, [that’s] the way I see it … It’s not that I was nearly dead and I was, I was saved. I was never on the edge of the cliff, from my viewpoint. I might have been, but I didn’t feel it … Yes, so I just see it, that I’ve been kind of let off the hook for a while.

He reported that the gift-of-life:

[I]s a good selling point. Yeah, a marketing thing. And there’s a tool for selling the concept to, to donors, yeah. That’s, that’s completely ok. Um, to the recipient? Don’t know, it doesn’t cross my mind to view it like that.

Anthony constructed his experience as involving a life prolonged rather than a life given; he was “already alive”. The distinction he makes here serves to take some of the moral force out of gift-of-life discourse. ‘Gift-of-life’ understandings of donated organs thus become a strategic marketing device (and “that’s completely ok”) rather than a ‘true’ reflection of what has transpired, or a guide to how he should understand his own experience.

Likewise, gratitude (in relation to transplantation) was not a strong feature of Doug’s narrative. He stated that: “for the family, I would say ‘thank you’. But would they want to hear from me? I don’t know”. He went on:

[You have to] look after the liver] but on the same token, you’ve got to get on with life … I try [pause] just to get on with life. That’s what you’ve gotta do. I’m not going to walk around all day going ‘Oh, I’m so grateful. I’m so grateful. Oh, oh, the world, I owe everything I have’. I’m not going to do that. Just not going to do that, coz that, then that detracts from you trying to get ahead in life, you know.
The extracts above show participants downplaying, or outright rejecting, gratitude in relation to their transplant. The narratives of some participants were largely reporting the negative aspects of their transplant experience (e.g., things they believed had been handled incorrectly or badly; ‘faults’ within the transplant system; things that had gone ‘wrong’), with little emphasis on the more positive features or outcomes. This might be attributed, in part, to the shaming nature of the response to those with ARLD receiving scarce resources. Awareness of their possible status as being undeserving (or less deserving) of a rare and precious ‘gift’ might lead to shame. In conjunction with this (or alternatively), focus on their transplant may be a constant reminder of illness and/or weakness, and associated reliance on others. This can be self-threatening (Fisher et al., 1982) and, for some, this identity-threat can lead to shame (Ferguson et al., 2000). Research has shown that gratitude is common following trauma or stressful life events (Teigen, & Jensen, 2011) and that it can play a significant role in healthy coping and recovery (Watkins, Cruz, Holben, & Kolts, 2008). However, shame might inhibit gratitude for some liver recipients (e.g., those with ARLD), and this might prove detrimental to long-term outcomes as they are denied the potential benefits of experiencing gratitude in this context.

6.7 Conclusions

Healthism, as an ideology, is now firmly entrenched in contemporary Western societies, and those who transgress by failing to follow the golden rule of living the ‘good’ (i.e., healthy) life are stigmatised (Galvin, 2002). The link between alcoholism and liver failure is widely acknowledged within the general populace, and those with alcohol-related liver disease (ARLD) are judged harshly (Ratcliffe, 2000). Most pertinently, in relation to liver
transplantation, the public can be critical of those with ARLD gaining access to scarce health resources such as donated livers: the consensus is they should be given lower priority as they are responsible for their illness, and therefore less deserving of these ‘gifts’ (Wittenberg, Goldie, Fischhoff, & Graham, 2003). In this study we explored the experience of liver transplantation, within the broader context of organ transplantation. We were particularly interested in exploring the experiences of gratitude and shame in relation to liver transplantation, given the judgments that are made of those with liver disease, and the risk of ARLD acting as a shame trigger and leading to a sense of undeservingness in this context.

Many participants in this study distanced themselves from healthism discourse and generally accepted worthiness narratives; instead, they engaged in pre-emptive ‘confessing’, speaking openly, and without prompting, of their ‘irresponsible’ (i.e., excessive) consumption of alcohol/drugs. The experience of transplantation for these liver recipients seemed largely informed by shame discourse. Shame is associated with denying, hiding or withdrawing from the shame-eliciting situation (Sheikh & Janoff-Bulman, 2010). We questioned why these participants would speak of their previous alcohol/drug abuse rather than attempt to avoid disclosure. We contend that in the context of transplantation, it is difficult for them to gloss over, or minimalise, their transgressions; unless they are totally ‘clean’ (like Lydia and Joan) they have to accept their actions contributed to their predicament. This ‘defective self’ is revealed to, or presumed by, all involved in the biosocial community of liver transplantation through the processes involved in waitlisting.
Work became a key site for establishing value and worth for those who had drawn heavily on society’s resources (in terms of healthcare) and yet, by virtue of their ‘irresponsibility’, might be considered unworthy of receiving such benefits. Unlike heart recipients, who based deservingsness on good past behaviour (Authors, in press), many participants in this study (who could not claim the ‘good living’ past) emphasised work as their contribution to society. All the male participants spoke of how ‘hard’ they had worked throughout their adult years (pre-transplant), and most reported their desire to get back to work quickly post-transplant. George spoke of his return to work within nine weeks, which was “nine weeks too long”, and Anthony reported he was back at work within two weeks of leaving hospital. Even Doug, who spoke about his current inability to work, stressed he ‘could’ (and would) work if given the right kind of support. Work status seemed to be an important identity issue for him; his lengthy, and highly negative, discussion of being forced to rely on “the pension” and “government housing” indicated that he found this shaming. Through their emphasis on work, these participants managed to discursively (re)position themselves as being productive (and thereby, valuable) members of society, and establish their worthiness of receiving a transplant in this way.

Scheff (2003) postulated that “[s]hame is our moral gyroscope”; it signals moral transgression and, thus, strongly influences our experiences (p. 254). We contend that shame had a marked influence on the experience of gratitude in the context of liver transplantation. It would be incorrect to say participants were not grateful, as they all expressed gratitude for various aspects of their lives. Some participants, though, expressed little gratitude for their transplant. The reaction to an unearned gift (particularly a non-normative, ‘amazing’, kindness) might be shame, rather than gratitude (Exline et
al., 2012), and may lead to devaluing the donor or help received (Fisher et al., 1982). We found that participants with ARLD sought to devalue their donated liver; relegating it to the position of being merely “good medicine” rather than extending to it the awe reserved for something rare and precious. Devaluing ‘the gift’ in this way might make it easier for the ‘irresponsible’ to deal with feelings of undeservingness and shame (generated by healthism discourse).

As highlighted by Sothern and Dickinson (2011), the ‘good recipient’ must not speak openly of shame, anger or disappointment; instead he/she must adhere to the ‘explicit construction of care’ put forward by the transplantation community and deny the existence of these emotions. Likewise, Shaw (2012) noted the scripted or prescribed narrative forms available within particular discourses, which constrain what can be said and felt. Given their ‘apparent irresponsibility’, under the gaze of healthism, ARLD liver recipients might arguably struggle to find available discourses for candid discussion of all aspects of their transplant experience (particularly any shame they might feel in relation to their ARLD). This potentially leaves them feeling vulnerable and unsupported, and may prove detrimental to long term physical and psychological outcomes (Shaw, Bell, & Webb, 2012).

We do liver recipients a disservice by allowing gift-of-life discourse to perpetuate unchallenged. Gift-of-life rhetoric largely directs the experience of transplantation (regardless of the organ received). However, our findings indicate the experience of at least some liver recipients is at odds with the gift narrative, and cannot be unequivocally sited within gift-of-life discourse. Not all recipients understand their transplant to be the
*gift of life*, and the particular organ being transplanted influences how transplantation is understood and experienced (by the recipient).

The current research is exploratory in nature; however, our findings indicate further research in the area of liver transplantation is warranted. This might involve a more direct investigation of shame in the context of liver transplantation. Other valuable areas for research might include the experience of shame across the transplantation of other organs, and the influence of shame on gratitude in the context of transplantation. We have found a generic model of organ transplantation cannot be applied across the range of organs available for transplant. Advances in medical technology are leading to increasing demand for, and access to, transplantation as a treatment for end stage organ disease, and the complex range of experiences associated with transplantation need to be better understood. A more nuanced understanding of the range of psychosocial issues encountered by liver recipients has implications for the development of sensitive and effective pre-and post-transplant support services in this context.
CHAPTER SEVEN

The experience of kidney transplantation: Hope for the ‘gift of freedom’

7.0 Relationship of the paper to the thesis

In this chapter, I present the third, and final, of a series of articles in which I have explored the experience of organ transplantation. Those experiencing kidney transplantation were the focus of this paper. All participants were receiving dialysis treatment, and were on the waitlist for a kidney transplant.

As in the context of liver transplantation, I question the uniform application of a gift-of-life model of transplantation. My interpretative phenomenological analysis of participants’ interviews indicates that many do not understand a kidney transplant to be the gift-of-life. All participants referred to the freedom (from the restrictions of dialysis) that would come with an organ transplant, and a transplant was thus understood to be the ‘gift of freedom’ rather than the ‘gift-of-life’. I present my findings and discuss the implications of them in this paper.

The paper titled, The experience of kidney transplantation: Hope for the ‘gift of freedom’ will be revised for submission, to meet the author guidelines of the Journal of Health Psychology.
7.1 Abstract

Gift-of-life discourse is pervasive in the context of organ transplantation, and largely informs the experience of this treatment for end-stage organ disease. In this article we question the universal application of gift-of-life discourse. Donated organs might be viewed differently in the context of kidney transplantation, as dialysis can sustain life. We conducted semi-structured interviews with 10 participants (all on the kidney transplant waitlist) to explore the kidney transplantation experience. Interpretative phenomenological analysis revealed three themes: dialysis, suffering, and hope; hope as a social construction; and gratitude, and its vicissitudes. We found that kidney transplantation was constructed as the gift-of-freedom rather than the gift-of-life, and argue that the routine application of a generic model of transplantation might occur to the detriment of some of those concerned (i.e., organ recipients and prospective recipients).
7.2 Introduction

Without any hope, ordinary or grand, people are left with only inertness, terror, and despair (Knibbe & Verkerk, 2009, p. 170).

One might anticipate that the context in which organ transplantation is experienced in Western societies is the same (or at least, very similar) for all those who have received, or are waiting to receive, an organ. This context, however, may differ in a number of ways, influenced not only by personal circumstances but also by the broader social milieu within which it takes place. Sharp (1995), for example, postulated that organs for transplant (i.e., heart, lung, liver and kidney) vary on a number of dimensions that have important implications for the experience of transplantation. The most obvious of these, she argued, is the basis of need. Hearts, lungs and livers are life-saving organs; the need is urgent, and prospective recipients will die if a donated organ does not become available in a timely manner. Kidneys, on the other hand, can be considered quality of life organs, as treatments such as dialysis can replace the functioning of kidneys and those on dialysis can remain so for extended periods of time. Another of these dimensions is social worth: fewer hearts and lungs are available for transplant and these organs have higher social worth because of their scarcity; and it is more difficult to replace a heart or liver than a kidney, with greater surgical difficulty leading to higher social value. Sharp contended that organs can also be differentiated on the basis of their symbolic weight; hearts (equated with love, passion, the self, or soul) and lungs (‘the breath of life’), for example, “are loaded with powerful metaphors that define what it means to be human and alive” (p. 372), while kidneys are considered less ‘serious’ and, therefore, carry much less symbolic weight.
It would be ill-conceived, though, to infer that the experience of kidney transplantation is somehow easier or without serious consequence for the individuals concerned because a kidney is ‘just’ a quality of life organ. The context of kidney transplantation is often less urgent than that of heart, lung or liver transplantation, but the majority of patients waitlisted for kidney transplantation are on dialysis and may have to endure several years of this treatment before receiving a kidney. Although dialysis liberates these individuals from the limits imposed on the body by end-stage renal failure, it can be anxiety provoking (i.e., remaining alive depends on the dialysis machine), and involves an investment of time and energy that can be exhausting (Russ, Shim, & Kaufman, 2007). In her study of dialysis patients, Gordon (2001) listed the major disadvantages of dialysis as being: “physical discomforts (e.g., needle sticks and muscle cramps three times a week), dietary restrictions, medical and physical problems, emotional stress, and strain on one’s family and job” (p. 246). For some, the treatment can be as burdensome as the disease itself (Schulz et al., 2012).

Kierans (2005) noted that illness “shatters our illusions of the predictable, the linear; our unquestioning faith in the idea of the next step: a tomorrow!” (p. 342). In her study of the narrative constructions of chronic kidney failure, she found the experience of ‘time arrested’ to be a central theme, with dialysis magnifying time such that patients experienced life on dialysis as if it were standing still. She argued that it is this experience of life as being ‘on hold’ that orients dialysis patients towards the future, and projecting forward into an imagined future (in which a kidney transplant is received and dialysis is no longer required) enables coping in this context. Although not named as such in
Kieran’s study, it appears to be hope (i.e., anticipating envisioned possibilities; Parse, 1990) that propelled these individuals toward their desired ‘tomorrow’.

### 7.3 Hope

Petersen, Seear and Munsie (2013) argued that the rhetoric of hope is pervasive in the context of health and biomedicine, where a hopeful outlook is seen to be a font of resilience and motivation, from which springs the means to overcome adversity. Perhaps this is no more so than in the context of kidney transplantation where the dominant ‘gift-of-life’ discourse (Fox & Swazey, 2002) and the biopolitical epistemology from which this discourse originates, rest upon the back of hope. Thus, chronic kidney disease and its treatment are constructed in a way that prescribes both the individual’s experience of the disease (e.g., dialysis patient, gift-of-life recipient) and his/her moral understanding of it (Shaw, 2012), with hope navigating the course through initial diagnosis to therapeutic resolution.

Research has indicated that hope may be a potent factor in coping. Chang and DeSimone (2001), for example, found that hope was inversely related to dysphoria, and significantly influenced coping. Billington, Simpson, Unwin, Bray and Giles (2008) reported that dialysis is often burdensome and restrictive as it entails strict adherence to inflexible routines, and those receiving this treatment commonly experience side effects such as discomfort, fatigue, scarring and infections. They investigated the role of hope in adjustment to the physical and psychological challenges of end-stage renal failure and dialysis, and found that higher hope predicted lower levels of anxiety, depression, and reported symptoms and burden of kidney failure. Higher hope also predicted improved mental health quality of life. Billington et al. argued that hope reduced the emotional
impact of kidney failure and dialysis, and the disease and its treatment were thereby perceived as being less burdensome.

It is important to note that those who undertake hope-related research have not adopted a single model of hope. Synder’s (2002) conceptualisation of hope, as a goal-oriented process necessitating both agency and pathways thinking, has been widely adopted in research. However, Kim, Kim, Schwartz-Barcott, and Zucker (2006), argued that all persons (i.e., the healthy and the ill) do not experience hope in the same way. They questioned the application of a goal-oriented model of hope among the chronically ill, and found that the conceptualisation of hope as a unitary, goal-oriented, construct does not accurately reflect the hoping experiences of chronically ill hospitalised patients.

Walker (2006) outlined a model of hope potentially more suitable in the context of health and healthcare. In her model, four features occur together in imprecise, and changing, proportions in the constitution of hope: futurity (hope is always future-oriented); desirability (the hoped-for outcome is valued by the hoping person); ‘nonzero’ possibility (the hoping person must believe the hoped-for outcome, however improbable, is possible); and efficacy (the dynamic tendency to engage desire and agency in a way that leaves the hoping person’s situation open to the desired outcome). Knibbe and Verkerk (2009) argued that this model has particular application in healthcare settings where patients’ hopes can be non-specific (i.e., patients might hope for ‘best possible outcomes’ rather than particular outcomes) and readily change over the course, and treatment, of an illness.


7.4 Gratitude

Gratitude is a positive emotion, typically experienced when an individual perceives that he/she has received an intentional benefit from another (McCullough & Tsang, 2004). Gratitude is normatively expected of transplant recipients, where gift-of-life discourse prevails and the donated organ is equated with the gift of ‘life’ itself (Fox & Swazey, 2002). Research has indicated that gift-of-life rhetoric is pervasive in the context of transplantation, and has the capacity to prescribe and direct this experience (Shaw, 2012). It entails performance of the ‘good prospective recipient’ and ‘good recipient’ roles as a demonstration of worthiness and gratitude for ‘the gift’ (Sothern & Dickinson, 2011). We were particularly interested in exploring gratitude in the context of kidney transplantation, given the dominance of gift-of-life discourse in both healthcare and public domains, and the competing understanding of kidneys as being potentially less valuable (i.e., quality-of-life rather than gift-of-life organs).

Individuals in the context of cadaveric kidney transplantation (such as those in the current study) need to adjust to a number of life-altering transitions as their disease progresses: diagnosis of end-stage kidney disease; living on the transplant waitlist; waiting for a kidney to become available under (what they presume will be) highly distressing circumstances for another person; dialysis throughout this period, transplant surgery; and life post-transplant, with all that entails (e.g., immunosuppressant regimen, fear of organ rejection/failure). A growing body of research attests to gratitude’s function as a coping factor in a wide range of settings: adjusting to crisis events, such as the September 11 terrorist attack on the United States (Fredrickson, Tugade, Waugh, & Larkin, 2003) and Southeast Asian Tsunami disaster (Teigen & Jensen, 2011); death
anxiety (Lau & Cheng, 2011); and breast cancer (Ruini & Vescovelli, 2013). Algoe and (2012) highlighted the importance of studying gratitude in the context of profound chronic stress (e.g., life-threatening illness), where its significance as a resilience factor in such circumstances might be revealed. They postulated that gratitude serves to foster high-quality communal relationships, and its adaptive value lies in the positive associations between such relationships and both physical and psychological health outcomes.

Given the research demonstrating the role that hope and gratitude can play in the facilitation of coping, we believed it important to explore these constructs in the current setting. We focused on the ways in which participants might engage hope and gratitude in managing their lives while on dialysis and after receiving a kidney transplant.

7.5 Method

7.5.1 Participants
There were ten participants in this study (i.e., two women and eight men). Ages ranged from 45 to 76 years ($M = 58.11$). One of the men was on the transplant waitlist (four and a half years) when he was first interviewed. He received a kidney transplant during the data collection period and was therefore interviewed a second time. The remaining participants were on the transplant waitlist; time on the waitlist (and on dialysis) ranged from six weeks to two years and eight months. One of the participants had received a (live) kidney donation from a relative but the kidney later “died”, and she was on the waitlist for a second transplant.

While this study is based on the interviews of these nine participants, it forms part of a larger study in which recipients of heart or liver transplants also participated.
7.5.2 Ethics

Approval for this research was received from the Human Research Ethics Committee of (redacted) University and also the hospital from which participants were recruited. The first author mailed a Participant Information Sheet (PIS) and an Invitation to Participate to all those on a list provided by a nurse practitioner, employed by the Department of Nephrology at the hospital. The PIS included complete details of the study: participation requirements; an outline of confidentiality processes; possible adverse effects; voluntary participation and withdrawal; contact details for the first author and also sources of additional information; and an offer to conduct interviews at a location chosen by the participant (i.e., his/her home, a private office in the hospital or the university).

The first author conducted all interviews, and each participant signed a consent form at the outset of his/her interview. Interviews were initiated with a general question (i.e., “Perhaps you could begin by telling me what led up to you being placed on the waitlist?”) aimed at giving participants a starting point for their narrative and settling them into the interview. Prompt questions were used where participants did not address a particular point of interest. These questions focused on participants’ thoughts and feelings about aspects of their transplant experience (e.g., being on the waitlist, undergoing dialysis, general feelings of gratitude or indebtedness, gift-of-life understandings of transplantation, and expectations for the future). At the end of the interview, we provided each participant with a card outlining a number of support options (should he/she experience any adverse effects). These options included contact details for: the interviewer; support services at the hospital; psychology clinic at the university; and two agencies that provide 24 hours a day/7 days a week telephone counselling).
7.5.3 Approach to analysis

We adopted interpretative phenomenological analysis (IPA), based on the understanding that the patient offers an ‘expert’ perspective on the psychosocial aspects of his/her illness (Sakala, Gyte, Henderson, Neilson, & Horey, 2001). Biggerstaff and Thompson (2008) argued that IPA is a particularly efficacious approach to the exploration of illness experience and how meaning is made in this context.

We followed the process of IPA outlined by Willig (2001): the first author read all of the interview transcriptions several times; from this, preliminary themes were identified and labelled; these themes were discussed across a number of meetings with the second author; conceptually related themes were clustered; and a summary list of superordinate themes, with supporting illustrative extracts, was produced. Murphy, Dingwall, Greatbatch, Parker, and Watson (1998) noted the influence a person’s a priori assumptions might have on data collection and analysis. The first author experienced a deep level of engagement in this research and, with a view to developing reflexive awareness and engaging with participants and their narratives more openly, she kept a reflexive journal throughout the entirety of this study.

7.6 Analysis and discussion

7.6.1 Dialysis, suffering, and hope

According to Kierans (2005), the modern biomedical narrative directs patients along a linear trajectory from diagnosis through treatment intervention to therapeutic resolution. She found that kidney patients adopted this biomedical imperative as it enabled them to deal with the rigours of dialysis, en-route to an imagined future in which a kidney transplant would resolve many of their health problems. At the outset of the present study,
all participants were on dialysis and were on the transplant waitlist. Many of them spoke of the extent to which dialysis consumed their lives, both in terms of the actual time spent in treatment as well as the mental burden of needing to plan all other activities to accommodate it.

Alan, for example, reported that he had been on dialysis for four and a half years; he had to go into hospital three times a week and was “on the machine” five hours each time. He stated that although some people feel well after dialysis, he is “always sick” (e.g., “nauseous”, “dizzy”) and this means “[he] can’t do anything” afterwards. He went on to report “there’s a lot of things you can’t do” because of dialysis, and that one of the things that bothered him most was the restriction on fluid intake: “it’s the water restrictions that really, really, annoy me. Yep, I really, that’s really starting to get to me”. Alan spoke at length on the topic of fluid restrictions, moving on from the topic and returning to it several times. He reported that he weighed himself every day in order to calculate how much he could drink, and that he had become “obsessed with drinking”. He went on to say, “sometimes you get down” because of the restrictions, and that “[e]very day I wish for a kidney. . . . Yep! Wake up . . . I want a kidney. Today is the day”.

Alan reported all of these disadvantages across his interview. Despite these difficulties, there was no sign of self-pity in his narrative. It seemed that hope for a kidney (and a quality of life similar to that of his sister, who had previously received a kidney transplant) gave meaning to dialysis, the sickness it caused, and the restrictions it imposed on his life. As highlighted by Billington et al. (2008), hope functions to lessen the impact of ESRD and its treatment, reducing the emotional burden. Hope, in this sense, is evident
in Alan’s articulation of dialysis as being “positive”; he was alive “coz of the machine basically”:

Because if you don’t go on the machine, you die. So it’s as easy as that. Bang! [clicks his fingers] . . . I’m on that machine, and the machine’s the gift of life to me. At the moment, that’s what’s keeping me alive. . . . [A kidney] will give me a [different] kind of a life. I’ve got a good life now.

Alan received a kidney and was interviewed a second time, approximately four months after his transplant. He stated that:

[he] got diabetes through the drugs. . . . Yes, unfortunately. Wasn’t very happy about that. . . . At one stage there I was bloody, I thought, bloody dialysis is better than bloody diabetes. That’s how bad I thought it was. Yeah, I just didn’t like it at all. Just hated it. I’ve got used to it now, kind of. But at first, I just hate, hate, hate. Just really hated it.

He reported the difficulties of dealing with both transplantation and diabetes. For example, he stated that his life had become very “regimental”; he had to test his blood sugar regularly, give himself injections regularly, and be careful about taking his immunosuppressant medications at the right time. He stated that he experienced side effects as a consequence of the immunosuppressant medications (e.g., diarrhoea), and was back on a restrictive diet – this time because of diabetes. Again, though, optimism was a feature of his narrative. Although initially despairing (i.e., “I thought, bloody dialysis is better than bloody diabetes”), he was learning to adapt to diabetes and hope gave meaning to his suffering, sustaining him through yet another difficult time in his life. As noted by
Petersen et al. (2013), hope is a valuable resource in the context of illness as it illuminates the path forward (i.e., hope can offer the means by which to direct current actions towards desired outcomes).

Much of Alan’s interview involved discussion of his plans for the future: his commitment to “saving money, so [he] can travel”; and his commitment to dealing with his diabetes so that it did not impinge on these plans. Billington et al. (2008) argued that a hopeful person is more likely to look at problems as challenges to be overcome rather than insurmountable obstacles, and Alan articulated hope in this way. He reported that he was doing, and would continue to do, “everything [he] can to look after [his kidney]. Definitely, yeah”. He had developed a daily routine that enabled him to cope with the necessary medications, for both transplant and diabetes, while maintaining employment. He recalled that while diabetes had initially been of great concern, he: had learned how to get his insulin levels “right”; took lollies in his bag wherever he went, and also the “little doodad” for measuring sugar levels; had sourced a number of sugar-free foods so he did not feel that he was missing out on sweet foods; and had become more physically active as the nurses told him he had “to exercise for the diabetes. They reckon half an hour a day”. Each of these actions represents a strategy for increasing the odds of the good outcomes that Alan is looking for – a behavioural enactment of hope. By carefully adhering to his immunosuppressant regime and also that of his diabetes, Alan moves himself toward an imagined future in which he experiences relatively good health and, consequently, the ability to travel.

Like Alan, most participants attended to their imagined future/s in a way that moved them towards ‘making it so’ (Walker, 2006), and the vision of a better future thus
gave meaning to their ongoing struggle. Although they outlined the negative effects dialysis had on their lives, they also recognised dialysis as the source of life (e.g., Luke: “dialysis is life. Um, you stop dialysis, you die”). They spoke of much-anticipated futures in which they received a transplant (no longer needing dialysis), experienced (relatively) good health and quality of life, and gained the “freedom” to follow their dreams. Greg’s narrative, however, stood in sharp contrast to these others. He told his story with a sense of hopelessness; he was brought down by the experience of needing a transplant and all the anxieties it evoked for him.

Greg reported that he experienced a “sense of disaster” when told he would need a kidney transplant, and that “the waiting’s the most difficult part, you know. Coz it’s a bit like being on death row [laughs nervously]”. He stated that his experience of dialysis had been disappointing: “I thought it’d take my, it would take my kidney function back up to, you know, nearly 100%. But it only ever takes you up about 10, you’re operating at about 10%”. He went on to speak about how dialysis affected him (e.g., reduced levels of energy, drive and libido; and a “decline in intellectual activity”), and that his hobbies had been “shut down” because of it. Much (indeed, most) of Greg’s narrative was taken up with his concern regarding the “lack of information” received about the “actual process of transplantation”. “There’s a lot of ‘nuts and bolts’ that we aren’t told”:

[T]hings like an ambulance . . . things like that, you know, need to be sorted. . . . And, there’s doubts about what I need to bring [to the hospital]. Would I need to shower, or if that happens at the other end. You know, all the bits and pieces. What drugs do I bring? Um, yeah. I’ve got a list on the fridge, of things I’ve
thought of... Like, where to go? Ah then, to have everything that, like to bring, on a list. So, I, I’ve got a bag that I can pre-pack.

When Greg was asked about the differences he thought a kidney transplant would make to his life, he replied:

That’s the thing, they don’t tell you. Ah, a friend of mine, her partner had a transplant. . . . And it made a hell of a difference. Energy, and energy levels. Sort of things like that. . . . But the [transplant team] don’t really tell you the upside, very, very much. So it’s something that needs to, to be emphasised more, you know. . . . So, it’s, and running the other way, ah you’re not . . . you’re not told what the downside is, of the drugs, you know. And what side effects are, and ah, I think it would be handy to know that before getting involved. The better prepared I am, the better I’ll be able to respond to it.

Greg’s narrative revolved around his anxieties concerning issues both large (e.g., the side effects of immunosuppressant medication) and small (e.g., what he should ‘pre-pack’ in his hospital bag). Even when a future-oriented question was posed (i.e., a question regarding his expectations of life post-transplant), he made only a ‘passing’ comment about his friend’s partner (who experienced higher energy levels) and then returned quickly to further discussion of what he had not been “told” about transplant.

The features of hope (e.g., futurity, desirability, efficacy) outlined by Walker (2006) were not evident in his story.

In a study of hope in patients with congestive heart failure, Ratajska (2008) noted that hope served to counterbalance fear, anxiety and fatigue. She argued that a patient’s
hope is one of his/her ‘chief assets’, as it enabled optimism, while giving meaning to those actions carried out in anticipation of desired outcomes. In the Billington et al. (2008) study of individuals with ESRD, higher hope predicted reduced anxiety, depression and disease-related burden, and was positively associated with good mental health quality of life. With indications of only the faintest of hopes in Greg’s story, there was little to offset his mounting anxieties about transplantation or to give meaning to dialysis and the deleterious effects he stated it had on his quality of life.

**7.6.2 Hope as a social construction**

Hope depends on a responsive social world; not necessarily a world that delivers hoped-for outcomes but one in which the meaning and value of hopeful efforts are, in some way, recognised and supported (McGeer, 2004). Walker (2006) argued that a hoping space is socially constructed in the nexus of available biotechnology with both the knowledge and expertise of those who administer this treatment, and the relationship between these healthcare providers and their patients. An example of this can be seen in Matthew’s report of the relationship he has with his nephrology doctor: “I couldn’t, I couldn’t say enough about the man positively. He’s, one thing he instilled in me right at the start is there is a light at the end of this tunnel”. Matthew reported that in the early stages of his illness he did not strictly adhere to the advice given to him but as he reached a more critical point in the progression of the disease, his doctor said to him: “this is what you’re going to have to do, okay?” Matthew went on to say:

[H]e was what I needed. That’s what I needed, you see. . . . I needed to be told. So from that . . . in me just came this respect for him, you know, this, and then as our relationship’s got going along, you know, over the past five years, you know, I’ve
learned to um, to take heed of his advice. So, um, I think of him in very high regard, yeah, of course. . . . And I’ve tried to do as good as I can, to do what he tells me to do. Yeah, I’ve got a lot of time for the man.

Westburg and Guindon (2004) postulated that hope is a necessary component of healing. In the context of treatment provided to HIV patients, they found that healthcare providers played a pivotal role in the generation and maintenance of hopefulness in their patients, and that hope was contagious in this context (i.e., hope was both ‘caught’ and ‘given’ in a bi-directional flow between healthcare provider and patient). Individuals have different economies of hope, in which their attention, energy, actions and thoughts are invested in hope in varied ways (Knibbe & Verkerk, 2009). For some, like Matthew, hope is based on the relationships developed with healthcare professionals, and the trust placed in these individuals. In the extract above, Matthew attended to the future by committing his energy and actions to “do as good as [he could]” to follow the advice of the doctor he held in such “high regard”. At several times throughout the interview he spoke, in highly positive terms, of this doctor (“the man is incredible”) and the nurses on the transplant team (e.g., “I have the utmost respect for them and their profession”). Matthew’s hope is articulated in his statement of the “light at the end of the tunnel” being “instilled” in him by the nephrologist. Via the respect and trust afforded this doctor and the transplant nurses, Matthew actively engaged these individuals in his hoping. Heeding their advice, he constructs an environment he perceives as being open to positive outcomes.

A ‘responsive social world’ also played a role in Bill’s hoping. He spoke animatedly, and at length, about an exercise class that he was involved in, discussing the importance of keeping fit (e.g., “the doctors always say ‘try to keep fit’”) but also noting
that he “love[s]” the social aspect of these classes. He stated that several of the class members were nurses (or “ex-nurses”), and recalled a conversation with one of them:

… one of the nurses, funny enough her sister is on dialysis as well . . . [and] she said: “Bill”, she said, “if you’re going to have a chronic disease, kidney disease is as good as any to have. At least they can plug you in, sort it out, keep you going.

Hope is embedded in the relationships outlined here. Bill attends to his doctors’ advice and, in so doing, there is hope for ‘best possible outcomes’ in the near, and more distant, future (i.e., fewer difficulties with dialysis; higher chance of successful transplantation; fewer problems post-transplant). Hope is also evident in Bill’s relationship with the nurse in his exercise class. A healthcare provider (although in a social capacity) with a sister on dialysis offers both ‘professional’ and personal insight, and in doing so ‘gives’ Bill hope that dialysis can, and will, “sort it out” and “keep [him] going”.

Bill recalled several conversations he had with nurses on the transplant team. Like Matthew, he developed relationships with these healthcare providers over the course of his treatment and the trust placed in them (and their expert advice) served to foster his hope. He reported that he was offered a kidney that “might” have been infected with HIV, saying that he immediately had “reservations” and after speaking with his wife he got back to the doctor and declined the offer. He was concerned that his rejection of the kidney might influence future prospects of receiving one, and the next day he phoned one of the nurses on the transplant team. He spoke of her reply: “Yep, we know all about it … it’s certainly not going to, you won’t be put down at the bottom of the list. And don’t worry; you weren’t the only one who knocked it back”. Here, the nurse reassured Bill that
passing up this particular kidney would not influence future opportunities, and his hope is thus maintained. He reported that the nurse went on to say:

Just remember Bill, it’s usually not as bad as [a kidney infected with HIV] but they’ve always got qualifications. Every time we ring, we’re never going to say: ‘this is the absolute perfect kidney, just ready for Bill Smith, you know. It, it’s from an old person, or they’ve done this, or something’s happened but we think it’ll be okay’.

Bill stated that this was “good advice” and, again, his hope is maintained in his trust that the transplant team will be honest regarding their professional assessment of any kidney offered, and that although not “perfect” the proffered kidney will be (in their opinion) “okay”.

Bill returned to the topic of the ‘rejected kidney’ several times, and justified his rejection of the opportunity for transplant in terms of imagined futures:

As soon as [the renal physician] was talking to me I could feel the emotions. Ah, I don’t, no, I don’t want AIDS. My sensible side was saying: “they can fix, if, if it turned to AIDS they can give you some drugs. It’s not going to kill you”. Um, I’m pretty sure that’s right. Well, then [if the transplant didn’t work] they, they probably wouldn’t give you another kidney because you’ve got AIDS.

He went on to say:

Literature I’ve been reading states that there is a 94% chance that [the kidney] will last 12 months. The second 12 months is the worst. . . . There’s a 100% chance
that it will reject at some stage. It could be in the first year. With a bit of luck it will be in 20 years’ time.

We see evidence of several imagined futures in these extracts, and it appears that hope helps Bill navigate them. In one of these futures, he accepts the HIV-infected kidney and develops AIDS. He has hope that AIDS will not “kill” him (because of available treatments), but when the new kidney no longer works (and he outlines the belief that this will certainly happen at some time) he has no hope of receiving a second transplant (i.e., they “wouldn’t give [him] another kidney” if he “got AIDS”). In another of these futures, he receives a kidney that, although not perfect, is “not as bad as” the one he declined. He acknowledges that early rejection is a possibility but hopes that for him, it might not happen for “20 years”. In this future he retains hope of a longer life, as there is a much better chance he will receive a second transplant if it is needed.

Hope was embedded in Bill’s reporting of his transplant experience. As he finished the interview he returned yet again to a discussion of healthcare providers:

[T]hey’re getting better. The drugs are getting better . . . They’re getting better at all of that stuff. So, so um, and I’m very confident in our surgeons. Our doctors are the best in the world. . . . I’m very positive about the whole thing. I think the system is very good. Not only the quality but the professionalism of everybody involved.

Although “[h]ealth professionals are not the gatekeepers of hope”, they do take on ‘hoping labour’ (Knibbe & Verkerk, 2009, p. 179). They are thus active in initiating and maintaining hope in their patients. This is evident in the examples outlined above, where
hope for both Matthew and Bill was kindled by those providing care and advice in the context of relationships developed over the course of their treatment. This was the case also for Malcolm (below), who relied on the opinion and advice of healthcare providers about new technologies available to him, and whose hope was ignited at an education seminar organised by transplant nurses.

Malcolm had been on dialysis for two and a half years, and reported that this had been a difficult time as, for him, dialysis was highly problematic. He stated that he had believed, because of his (advanced) age, the only kidney he would receive was a donation from a relative (i.e., one of his children). However, he had lived a (relatively) long life and “what’s the use in messing up their life”, so he dismissed this possibility, deciding that if he wanted “to stay on the world” he would have to deal with dialysis. Doctors then told him about the possibility of resected kidney donation:

They’ve got, have, have a new system now, with ah, um, older patients above 60. They um, people who’ve got cancer, they operate on their, take the cancer out. . . . Until recently they used to just throw that kidney away. But now . . . they check it all out, and cut it out, and stitch it up and put it back into the people that are over 60.

Malcolm stated that initially he had reservations about this idea but then had an experience that changed his thinking:

[W]e went to a seminar once and um, where a lady there, she’s only 68 but she had [a resected kidney] because . . . she hated the dialysis, you know. She dreaded the needle and all that, which I’m not worried about that, you know. Okay, and then of course she got this kidney which, she got it within two, two months. . . .
She says it’s marvellous and she danced on the floor [laughs gently]. She’s only 68. I’m [age]. But ah, no, we went for it then. We thought, um, we’d go for [a resected kidney].

Later, when asked about his expectations for the future, he stated:

Well, again, I’ll only refer to this lady, seeing this lady. . . . She, she was 68 . . . but she was dancing on the floor. Well I don’t expect to do that, you know, but I just want to be able to get up and do things, you know.

Malcolm spoke of the ‘dancing lady’ several times during the interview. He did not mention the risks inherent in the transplantation of a resected kidney, but focused instead on the joie-de-vie of this woman, who captured his imagination and activated hope for an imagined future in which he, too, would be more energetic. Nwoye (2011) postulated that hope is a two-tailed attitude; nurtured by factors within the hoping individual and also, importantly, by social factors. He argued that sharing testimonies, of personal hopes fulfilled, encourages the hope in others of realising a similar fate in the future. Based on imitation (i.e., if he/she can do it, I can too), such stories are active in the construction of hope. Hope, as social contagion, can be seen in Malcolm’s response to the education seminar, where he witnessed the possible outcome of receiving a resected kidney transplant. Hope was ’spread’ at the seminar not only by the testimonial of the ‘dancing lady’ but also by the healthcare providers who participated in organising the event, and their accounts of the many who have endured dialysis to reach transplantation and gone on to live “full” lives.
7.6.3 Gratitude, and its vicissitudes

All participants in the current study were on dialysis (while waiting for a kidney transplant) and existed in a state of persistent liminality, in which their understandings of sickness, health and normality were being constantly (re)negotiated (Crowley-Matoka, 2005). They reported (to varying degrees) their struggle with dialysis, as it represented the treatment for, and cause of, sickness. Transplantation was universally acknowledged as representing “freedom” from dialysis. Luke, for example, stated that transplantation is “the gift of freedom, more so than life. I mean, ah, dialysis is life. . . . Um, the gift of a kidney is more about freedom. To me.” Jacob expressed similar sentiments: “you are um, pretty well, you know, bonded to that machine, and ah, it’s, it’s your life and if you don’t have it, you die”. He stated that transplantation, to him, meant not “having to rely on [that machine]” and returning to “the freedom [he] had before [he] started dialysis”.

Participants thus indicated their belief that dialysis was keeping them alive. It might be anticipated, then, that their treatment would evoke much gratitude, and for some participants this was the case.

Lisa, for example, reported a number of seriously debilitating conditions, and treatments for these, before being diagnosed with kidney failure. She then had a sad and unfortunate experience of transplantation; she received a kidney from her brother but “it died” a short time later. Lisa recalled that she had felt a great deal of anger towards the doctors who had treated her:

I felt really, really angry with the hospital, with the um, with the doctors. The doctors, I still think, um, they missed something. Yeah, and that’s basically why I’ve ended up actually on dialysis and actually ended up on the cadaveric list. . . .
think the doctors, they move from one patient to another too quickly, and there’s not enough, you know, concentration on the one patient and something was missed. Something’s gotta, to me, something was missed in that, in that week when they were saying it’s gone into ATM [Acute Tubular Malfunction].

Although she returned to the topic of the doctors and the ‘death’ of her kidney several times, she stated that she had been seeing a psychologist who was helping her deal with all that happened, and “[i]t is past tense now. It’s probably something that will always live with me, but it is past tense”. She went on to say that in some ways she considered herself “fortunate because at least with a kidney transplant you can get a second go. Heart transplants and so forth, you’re not necessarily as lucky”. Unprompted, Lisa spoke of some of the positive aspects of her transplant experience (e.g., the treatment, care and advice received from the transplant nurses), and there was evidence (as in her comment above) that she sought ‘a silver lining’ in some of the more negative aspects. When asked if there was anything in her life that she was thankful or grateful for, she responded without hesitation: “At the moment, I just say: ‘thank God I’m alive’”. She spoke of working in healthcare and seeing people who are very ill:

Ah, I look at them and think how sick they actually look and yet they’re getting up one morning after the other. Putting one foot in front of the other. Um, and for myself, I just say: ‘Thank God I’m actually alive and I can actually do this’ . . . . I’m thankful that my brother tried to do the kidney transplant. Ah, I’m thankful that I’ve actually come this far through it and can have another go at it. Er, I have a massive, I’m very thankful for the massive amount of support that I got from
people from my local area and the parish that I go to, and the people that I meet
down the park and so forth, that helped me out during that particular time.

The comparisons that Lisa makes with others she considers to be less fortunate
than herself represent downward counterfactuals, where focus is placed on how the
situation could be worse (e.g., she could have been a heart recipient, and unable to “get a
second go” at transplant; or she could be as ill as the patients she sees at work, who are
unable to do some of the things she can currently do). Research has indicated that
downward counterfactuals play a powerful role in the activation of gratitude (Teigen,
1997; Teigen & Jensen, 2011), as gratitude by virtue of its definition involves the receipt
of a benefit that might not have come one’s way. In a study of kidney recipients’ quality
of life, Orr, Wilis, Holmes, Britton and Orr (2007) found that participants made
downward comparisons with their pre-transplant time on dialysis, which served to
generate positive feelings of being ‘lucky’ and enabled coping with the difficulties of life
post-transplant. One of the mechanisms undergirding this effect might be a sense of
coherence, defined by Lambert, Graham, Fincham, and Stillman (2009) as an
understanding that life is manageable, meaningful, and comprehensible. Lambert and
colleagues found that gratitude is linked with increased sense of coherence, through
positive reframing (i.e., benefit-finding or positive reinterpretation). Sense of coherence,
in turn, predicts a number of positive outcomes, including enhanced coping with critical
illness (Fok, Chair, & Lopez, 2005).

Although some participants spoke of many things for which they were grateful,
others did not mention gratitude at all. Sonia, for example, reported that dialysis “wasn’t a
nasty shock” because her doctors had discussed it with her on a number of occasions, and
she knew it “was going to be an eventuality”. She stated that she generally felt “ok” since going on dialysis, and this was a big improvement on her pre-dialysis health when she “literally had to drag [her]self around”. Sonia recalled the treatment she had received over a period of several years as her kidney disease progressed, and the dialysis equipment and supplies that had been provided so she could undertake dialysis at home. She had not mentioned thanks or gratitude at this point, and when asked if there was anything in her life for which she was thankful/grateful, she paused (for fifteen seconds) and then stated “No, there is, there isn’t, no”.

Sonia was on the transplant waitlist, and remained on dialysis throughout the course of this study. Gift-of-life discourse suggests that a person should be primarily grateful for receipt of ‘the gift’ (an organ transplant), not necessarily the medical treatment that keeps him/her alive until a transplant is received. However, the moral imperative of gratitude suggests that it is experienced when a valued benefit has been received, and the benefit was given intentionally and at some cost or effort to the benefactor (McCullough & Tsang, 2004). It appears that, for Sonia, the ‘prerequisites’ for gratitude had not been met. This may be due to her understanding of the treatment she has received. That is, she might understand this treatment to be an entitlement rather than a ‘benefit’, which, under different circumstances, she might not have received. Where there is a sense that one is entitled to something (e.g., healthcare, or education, in many Western societies), it might not be perceived as ‘a benefit’, as such, and it is then less likely that gratitude will be experienced.

Participants, like Sonia and Jacob (below), who expressed little gratitude, tended also to include few others (e.g., family members, friends, healthcare providers) in their
stories. Their narratives were less social, constructed around ‘me’ rather than a more inclusive ‘we’ (in which others were included in their recollections of treatment, support, care, current living and future plans). Matthews and Green (2010) found that high self-focus, with much attention directed inwardly toward one’s thoughts and feelings rather than outwardly towards others, inhibited gratitude. Highly self-focused individuals were likely to experience a greater sense of indebtedness (with its more negative affect) than gratitude, and also less commitment and closeness to those who benefitted them.

Jacob reported that he had initially “avoided [dialysis] like the plague” and “dreaded” the very idea of it but in hindsight wondered why he was so averse to the idea. He had “been getting progressively worse and worse” and:

dialysis does, ah, help your health in a lot of ways. . . . [y]ou get your health back and, the actual energy levels and, um, just wellbeing increases once you actually, you know, start getting rid of the toxins in your blood.

Despite reporting the benefits of dialysis, Jacob emphasised the ”restrictive”, “awkward” and “cumbersome” aspects of it. He spoke of not being able to travel and of all of the equipment that was required for dialysis, and there were caveats throughout his narrative that served to emphasise some of the more negative aspects of this treatment. For example, dialysis kept him alive but it was restrictive:

it’s a major exercise to put all your gear in the car and go [down the country]. . . .

[T]he back of the, ah, seat is absolutely crammed full and stuff, stuff in the boot as well, and that’s just for ah two days.
The hospital supplied all of the necessary equipment and “you’ve got no cost at all”, but “[y]ou’ve got storage of, you go through um probably a box, you know, a box containing two, five-litre bags, ah, every night so you’ve got a, a room full of equipment”. Jacob did not raise the topic of gratitude, and when a gratitude question (i.e., is there anything in your life for which you are thankful or grateful?) was posed, he replied: “Nothing, nothing really, um, sort of springs to mind that’s highlighted”. He paused for several seconds and then said:

Um, the fact that I’m still living and still kicking along is one thing I’m grateful for. Um, yeah having, yeah, the support to actually do what I’ve done . . . . Um, I’ve always been, you know, very um prepared to do anything, you know, to do whatever I want, that sort of thing. So um, I sort of make my own, um, good fortune, I think really.

As with Sonia, it appears the conditions on which gratitude is based (McCullough & Tsang, 2004) were not realised for Jacob. This might be due, in part, to his attribution of “good fortune” to himself (i.e., “I sort of make my own, um, good fortune”), rather than another (i.e., a benefactor who intentionally expended cost/effort on his behalf). Buck (2004) argued that for gratitude to be activated, the receiver of a benefit must experience humility in relation to the benefactor. That is, the receiver must “perceive and acknowledge that said benefit is related to the power and goodness of someone or something else” (p. 106). He went on to argue that an inability to experience humility when a benefit had been received impaired gratitude. The work of Kruse, Chancellor, Ruberton, and Lyubomisky (2014) supported this line of thinking. They identified humility as an outward, other-focused state, which has the capacity to shape and enhance
the experience of gratitude. Humility and gratitude were shown to positively predict each other in a mutually reinforcing upward spiral.

Some participants reported gratitude in relation to their treatment, but this was not the case for all. What lay at the heart of this appears to be the focus of attention. Lisa, for example, made downward social comparisons and this served to highlight the ways in which her life might be worse (i.e., like some of those she compared herself with, she might be too ill to undertake many of the activities she was able to enjoy). This focus elicits an appreciation for life and what one has (i.e., tangible and intangible assets) that is typical of the grateful (Wood, Maltby, Stewart, & Joseph, 2008). The narratives of others, in contrast, indicated an inward focus that is not conducive to gratitude (Matthew & Green, 2010). The narratives of some participants led us to the view that they might understand their treatment as an entitlement of the society in which they live rather than a benefit, per se. Even though many participants constructed dialysis as the gift-of-life, it is not as clearly situated within the social discourse that constructs donated organs (rather than medical treatments) as ‘gifts’. A focus on what they have not received yet, a kidney, or on the more negative aspects of their treatment is not likely to lead to the cognitive processing (e.g., benefit-finding) that is associated with gratitude (Wood et al., 2008).

7.7 Conclusions
As long as dialysis is available, those with end-stage renal disease (ESRD) can experience a ‘non-emergency’ disease status (relative to those with end-stage heart or liver disease). This sets kidney failure apart from these other diseases requiring organ transplantation. We explored the experience of kidney transplantation to further understandings of transplantation in circumstances that might be considered less dire. We had a particular
interest in exploring the psychosocial aspects of this experience, and in particular, the roles that hope and gratitude might play in facilitating coping in this context.

All participants were aware of gift-of-life understandings of transplantation but discursively (re)defined transplantation as the gift-of-freedom. Transplantation was thus relegated to a lesser role in their ongoing treatment for ESRD. It meant freedom from the inflexible routines that dialysis entailed, freedom from the restrictions dialysis imposed on their lives, and/or freedom from the discomforts/pain/sickness that some experienced as a consequence of dialysis. With respect to this redefined (gift-of-freedom) understanding of kidney transplantation, it could, thus, be viewed as a less valuable ‘gift’ than dialysis, and less valuable relative to other (life-saving) organs. We note that caution must be taken when interpreting these findings. Only one participant (i.e., Alan) received a kidney during the course of this study. When Alan was interviewed post-transplant, he reported that he was “happy” with his transplant, the good “definitely, definitely” outweighed the bad, and he would not like to have to go back on dialysis. However, he noted that the option of dialysis was available to him should his new kidney fail, and adhered to his pre-transplant position that kidney transplantation represented the gift-of-freedom (rather than the gift-of-life) to him.

Sharp (1995) noted that the symbolic weight assigned organs has profound consequences in terms of gratitude. Participants in the current study emphasised their understanding of kidney transplantation as the gift-of-freedom: although still a ‘gift’ of great value, one of arguably lesser status than the gift-of-life. Gratitude is generally elicited in response to benefits perceived to be of value (McCullough & Tsang, 2004), and there exists a normative expectation of gratitude in the context of transplantation.
(Sothern & Dickinson, 2011; Shaw, 2012). However, we found that participants did not always experience gratitude in this context. We argue this might be due to an understanding of treatments, such as dialysis and/or organ transplantation, as being entitlements rather than ‘benefits’ as operationalized in the generally-accepted definition of gratitude (McCullough & Tsang, 2004).

In the contemporary Australian context, dialysis is ‘an entitlement’ in the sense that patients have ready access (at little, if any, financial cost) to this form of treatment through the public health system. While entitlement, in a practical sense, can be of benefit to patients (i.e., they can access life-saving treatment by virtue of their citizenship), it could prove detrimental in the psychological sense. Feelings of entitlement might pose a barrier to the activation of gratitude, and those receiving treatment for end-stage organ failure could thereby lose access to what can often be a valuable coping resource.

Some participants spoke of dialysis as a privilege, and were mindful of the many others, often unknown, who had acted in ways that benefitted them. Focusing on dialysis as a benefit that in different circumstances they might not have received, they expressed much gratitude in relation to their access to dialysis, the effects of the treatment on their health, the healthcare providers who delivered dialysis, and those who supported them through it. These participants tended also to acknowledge, but not dwell on, the restrictions and impositions of dialysis. We cannot argue causality in the context of the present study. However, it is feasible to suggest that gratitude might have played a role in coping and adjustment in this context (Watkins, Cruz, Holben & Koltz, 2008; Watkins, Grimm, & Koltz, 2004; Wood, Joseph, & Linley, 2007). We suggest that gratitude’s role in coping with dialysis is an area that merits further investigation.
The mythological Pandora was left with only hope, and she was comforted by this awareness, as she believed that hope is sometimes enough. We found that hope lay at the core of participants’ narratives. They endured the negative aspects of the present (e.g., dialysis) ‘in hope’ of reaching imagined (and much-anticipated) futures. Research has indicated that adjustment is a dynamic, rather than static, process (Kendall & Buys, 1998). We suggest that hope might be powerfully influential in the context of kidney transplantation, guiding prospective recipients through a number of complex, and constantly changing, situations as they transit through dialysis towards transplant.

McCullough, Emmons, and Tsang (2002) found a strong association between hope and gratitude. Those in the current study who expressed considerable hope, also tended to report on the many things for which they were grateful: indicating that hope and gratitude might be close allies, with each fostering the presence and development of the other. Our preliminary investigation of the experience of kidney transplantation indicates that hope and gratitude might be potent factors in resilience and coping in this context. Further research utilising alternative research methods is warranted; particularly that which attempts to unpack the particular elements of gratitude and hope that are most likely to lead to increased resilience and coping in this setting.

Our findings expand on gift-of-life understandings of transplantation (Fox & Swazey, 2002; Shaw, 2010, 2012; Shaw, Bell, & Webb, 2012; Sothern & Dickinson, 2011). Participants in the current study constructed kidney transplantation as the gift-of-freedom. We found that in this context dialysis was constructed as the gift-of-life (i.e., participants reported their dependence on dialysis as a life-sustaining treatment, and there were fervent declarations that ‘dialysis is life’). This supports the findings of Authors
(under review), which indicated that the particular organ being received (i.e., liver, heart or kidney) informs the experience of transplantation, and the gift-of-life understanding of transplantation cannot be uniformly applied. Organ recipients (and prospective recipients) are not best served by the routine application of a generic, single and singular, model of transplantation that does not necessarily ‘fit’ with their experience. This may be particularly so in healthcare settings where the application of a model that does not ‘fit’ with the experience of those involved is likely to have the most pronounced influence.
CHAPTER EIGHT

Conclusion

People’s experiences are intensely personal; claims to the uniqueness of experience are true and deserve to be honored. . . . People’s ability to have experiences depends on shared cultural resources that provide words, meanings, and the boundaries that segment the flow of time into episodes. Experiences are very much our own, but we don’t make up these experiences by ourselves (Frank, 2013, Preface 2013, para. 8).

8.0 Introduction

All experiences, however personal they might be, are social in that they depend on ‘shared cultural resources’ in order to become meaningful human experiences (Frank, 2013). Organ transplantation is a ‘total social fact’ in the manner described by Mauss (1970) in his gift exchange theory. That is, it represents the (literal) exchange of a social resource (i.e., an organ, ‘gift’, taken from the body of one person, and placed into the body of another), which initiates and perpetuates ongoing relationships. It is also a social fact in that the organ transplantation experience is founded upon, prescribed, directed, and bound by gift-of-life discourse (Fox & Swazey, 2002; Shaw, 2012; Shaw et al., 2012; Sothern & Dickinson, 2011). As emphasised by Einstein and Shildrick (2009), it is important that a purely biomedical approach is not adopted when attempting to understand health, illness, and the effect of biotechnologies (like transplantation) on the individual and his/her life: failure to recognise and acknowledge the situatedness and
contingencies of a person’s life can prove detrimental to medical efficacy and appropriate care.

This thesis presents an analysis of the psychosocial organ transplantation experiences of heart, liver and kidney recipients and prospective recipients. Within this broader framework, I had a particular interest in exploring gift-of-life understandings of transplantation, as well as a focus on the emotion of gratitude and other affective responses to the gift-of-life. Although all participants had undergone what might, on the surface, appear to be the same experience (i.e., waiting for, and/or receiving an organ transplant), I found that their experiences were diverse. I did not encounter one, homogenous, group of transplant recipients/prospective recipients but instead, individuals who spoke about their experience of transplantation in strikingly different ways. Although divergence was evident, I found considerable convergence within the particular organ-groups, and thus made an analytic division along the line of the particular organ that had failed and had been (or would be) replaced. I presented my findings in three articles (included herein) based respectively on the heart, liver and kidney transplantation experiences.

The particular organ being received has distinct implications for the psychosocial/affective experience of transplantation. As I moved through the interviews with participants, I found that they were not all telling the story that one might expect (or at least what I might have expected): that is, the ‘gift-of-life story’, complete with morally expected (i.e., appropriate) levels of gratitude. What I, instead, encountered were many different stories, all replete with the struggle of “the ordinariness of the day-to-day” (Kierans, 2005, p. 343), and I grew to understand that not all organ recipients recognise
transplantation as the gift-of-life. The move away from a generic model of ‘the’ transplantation experience provides a more nuanced understanding of transplantation, its influence on the lives of those who experience it, and also that of gratitude (and other emotions) in this context.

8.1 Healthism: Transplantation in context

Transplantation does not take place in a void: like all human activities it is socially, culturally and politically situated, and occurs in the context of a number of, often competing, discourses. In many western societies, healthism (the moralisation of health) is the dominant ideology through which concepts of health and illness are framed (Crawford, 2006). Healthism might thus be regarded as the crucible of the contemporary transplantation experience.

Responsibility and culpability are the mainstays of healthism (Yoder, 2002). Under its gaze, healthy individuals are seen to be so as a result of making responsible (i.e., good/correct) choices: links between health and moral behaviour are assumed, and their health is seen to be evidence of life lived as moral and worthy citizens of society (Cheek, 2008). The issue of responsibility is also raised in the context of illness: questions are raised about the extent to which those who are ill, through their actions (or lack thereof), can be held accountable for their condition; and some forms of illness are open to more critical scrutiny than others. If those who are ill engaged in ‘irresponsible’ behaviour (e.g., excessive consumption of alcohol, drug abuse) that might have led to their illness, they are seen to have failed. That is, they failed to engage in appropriate self-management, and therefore failed to engage in society as moral citizens. As emphasised
by Galvin (2002), healthism raises the potential for societies, and individuals in these societies, to tread the slippery slope of judgment, blame and recrimination.

8.2 Transplantation as the gift-of-life

The gift-of-life metaphor is exploited in the context of transplantation. It is employed strategically in a bid to raise awareness of the scarcity of organs for transplant, position organs as rare and precious gifts that one person can give to another, and increase donation rates (Lauritzen et al., 2001; Siminoff & Chillag, 1999; Sothern & Dickinson, 2011). The gift-of-life metaphor is also utilised to engage recipients in a post-transplant ‘construction of care’, which ensures that transplanted organs (precious gifts) are not wasted (Sothern & Dickinson, 2011). However, this use of gift rhetoric has the capacity to condition, and even prescribe, the experience of transplantation and recipients’ moral understanding of what has transpired in the event of their transplant (Shaw, 2012).

Heart recipients endorsed the understanding that transplantation is, indeed, the gift-of-life. As argued previously, healthism opens the lives of individuals to scrutiny; they are judged on the basis of their health-related choices and behaviours, and are increasingly being held accountable for their health-status (Galvin, 2002). Heart recipients acknowledged awareness of being judged in their attempts to establish deservingness of the rare and precious gift-of-life. Many endeavoured to negate any sense of blame for their illness, and spoke of leading active/healthy lifestyles before being ‘struck down’ by illness. They reported, for example, exercising regularly, engaging in “good”, “clean” living (e.g., no smoking, little or no drinking of alcohol), and being careful to adhere to a good/healthy diet. Unlike liver recipients, the weight of expectation that they might be responsible for their illness was not as great for heart recipients.
Having established their worthiness, it could be that the social aspects of the transplantation experience are relatively straightforward for them. That is, it seems from these findings that the experiences of heart recipients are most closely aligned with the gift-of-life experience prescribed by gift rhetoric.

All are not considered equal in their time of need: the general public tends to judge those with liver failure harshly (Neuberger et al., 1998; Ratcliffe, 2000; Ubel et al., 2001; Wittenberg et al., 2003). As reported by Doug (liver recipient): “[The public ask], why are you wasting organs on eeuuww [alcoholics]? . . . You’re not perfect, you shouldn’t have that [gift-of-life]”. Sensitised by the social stigma surrounding liver disease, the experience of transplantation for some liver recipients (i.e., receiving an ‘unearned gift’, one they do not deserve) might be strongly inflected by shame (Exline et al., 2013). This can lead to the devaluing of the help (‘gift’) received (Fisher et al., 1982), and, in sharp contrast to heart recipients, many liver recipients in this study were forthright in their rejection of gift-of-life understandings of transplantation. Many downplayed the magnitude of ‘the gift’, and a comment made by Jack (liver recipient) reflected the general consensus of liver recipients participating in this research: [liver transplantation is] not a miracle, it’s simply good medicine”.

The context of kidney transplantation is not typically characterised by the same level of urgency as that of heart or liver transplantation, as those on the kidney transplant waitlist can be treated with dialysis. This can give rise to the perception of kidneys as being less valuable (i.e., quality of life organs) relative to hearts and livers (life-saving organs; Sharp, 1995), and has the potential to influence gift-of-life understandings of transplantation. Although less urgent than heart or liver transplantation, the context of
kidney transplantation is nonetheless medically and socially difficult. Many of those receiving dialysis have to endure years of suffering (e.g., discomfort, physical problems, emotional distress, and restrictions). The prospective kidney recipients in this study reported their understanding of a transplanted kidney as the gift-of-freedom. That is, something that would free them from the many restrictions dialysis imposes on their life.

Like liver recipients, the prospective kidney recipients emphasised that gift-of-life understandings of transplantation did not resonate with them. It is important to note, though, that only one of the prospective kidney recipients (Alan) received a kidney transplant during the course of this study. Alan’s pre-transplant stance remained unchanged after transplantation: he still understood a kidney transplant to be the gift of freedom, and not the gift-of-life. However, he “got diabetes through the drugs” (i.e., his immunosuppressant medications), and his circumstances represented the literal exchange of one set of problems for another. As he reported: “[a]t one stage there I was bloody, I thought, bloody dialysis is better than bloody diabetes”. It is possible that a less complicated post-transplant experience might alter the gift-of-freedom understanding of transplantation held by the kidney participants in this study.

### 8.3 Gratitude as reciprocation for ‘the gift’

The gift-of-life metaphor emphasises the magnitude of the exchange that occurs in organ transfer: it construes transplantation as the giving and receiving of life itself. As Frank (1995) noted, “metaphor establishes a storyline” (p. 57), and the dominance and ubiquity of the gift-of-life metaphor in the sphere of transplantation firmly establishes the transplant story as one that entails gratitude. Gratitude is expected as the morally
appropriate response to the receipt of the gift-of-life (and/or treatment that leads to the receipt of this gift). Although normatively expected in the context of transplantation, the moral imperative to be grateful was not taken up by all participants.

Gift-of-life understandings of transplantation appear to influence the experience of gratitude in this context. Heart recipients, who (of all the participants) most often spoke of their transplant as the gift-of-life, also most uniformly expressed gratitude in relation to their transplant. Hearts have higher social value than some other organs (Sharp, 1995). Sharp emphasised that compared to kidneys, for example, fewer hearts are available for transplant, heart transplant surgery is more difficult, and hearts carry greater symbolic weight. These factors, she argued, increase the social value of hearts and thus influence the activation of gratitude.

Heart recipients reported the negative side effects of immunosuppressant regimens. However, their narratives were those most closely aligned with the idealised version of organ transplantation. Their expressions of gratitude were expansive, and included family members and friends, donors and donor families, as well as the transplant team and other healthcare professionals. Although all heart recipients spoke of their gratitude, these gratitude experiences were more complex than the straightforwardly positive experience generally outlined in the existing gratitude literature. Gratitude was tempered by the other emotions present in the context in which it was experienced. For example, gratitude experienced in the context of celebration (for all that was received in transplantation) was joyful and hope-filled, while gratitude experienced in the context of disappointment (for continuing health problems and unfulfilled hopes) tended to be a
sombre experience with a more negative valence than that of gratitude experienced in celebration.

Gratitude was not a strong feature of liver recipients’ narratives. Few spoke of gratitude in direct relation to their transplanted liver, perhaps because of the context (e.g., social stigma and shame) in which liver recipients receive their transplant. Exline et al. (2012) found that gratitude was most often reported in response to normative acts of kindness, and less so in response to non-normative (i.e., what they called, ‘amazing’) kindness. They argued that ‘amazing’ kindnesses are more open to the perception of being undeserved, leaving the recipient of such kindness vulnerable to the experience of diminishment and shame, rather than gratitude.

8.4 Inhibition of gratitude

In the contemporary context of healthism, people experiencing liver failure are subject to judgments about their assumed ‘bad’ (antisocial, morally reprehensible) behaviour (Neuberger et al., 1998; Ratcliffe, 2000; Ubel et al., 2001; Wittenberg et al., 2003). This arguably leaves them prone to feelings of shame and undeservingness. As noted previously, gift-of-life rhetoric serves to emphasise the magnitude of the donated organ. That is, it underscores the ‘amazing’ kindness of the donor, and ‘amazing’ nature of the gift given and received in transplantation. With their status as good, moral, citizens of society already challenged through the lens of healthism, the ‘amazing’ nature of the gift might serve to exacerbate liver recipients’ feelings of shame, and inhibit the experience of gratitude in this context.

Kidney participants were divided in their expressions of gratitude. While some reported considerable gratitude in relation to their treatment, others reported little, if any
at all. Perceptions of transplantation, as either a privilege (a benefit that might not be available under different circumstances) or an entitlement (something that one should receive as a citizen of a technologically advanced society like Australia), appear to bear on the extent to which gratitude is experienced in this context.

Engaging in downward counterfactuals (i.e., comparing one’s situation with that of others in less fortunate circumstances, and realising that one’s own situation could be worse) can give rise to feelings of being privileged, and activate gratitude (Orr et al., 2007; Teigen, 1997; Teigen & Jensen, 2011). However, treatments like dialysis might be less straightforwardly understood as ‘benefits’, as defined in the gratitude literature: that is, something of value, which is intentionally given to the recipient by the benefactor, and given at some cost or effort on the part of the benefactor (McCullough et al., 2001; McCullough & Tsang, 2004). For some Australian citizens, dialysis might be understood as a right rather than a privilege; something afforded those with kidney disease, who have recourse to the Australian health system. This understanding might feasibly inhibit the experience of gratitude.

8.5 Gratitude experiences

Experiences of gratitude outlined by participants in the current study give rise to a more finely nuanced picture of gratitude than has been accounted for in the current body of gratitude literature. Gratitude experienced in isolation is a positive emotion and I do not argue that it is anything other than this. However, gratitude is almost invariably experienced in association with other emotions, some of which may contradict its positive nature. Gratitude for a donated organ, for example, may be accompanied by guilt associated with the (secret) wish/hope that an accident would occur and result in an organ
becoming available. As a result, the *contextualised* experience of gratitude is often more complex than the ‘unadulterated’ account of gratitude that is generally referred to. I draw on the emotion of love as a parallel here. Love is typically thought of as a positive emotion. However, love can be a contradictory experience in the context of rejection, jealousy, betrayal, or death of a loved one. In these instances, love is less than strictly positive: indeed, it can be a painful experience, with a strong negative valence.

The emotion of gratitude cannot be separated from the other emotions that occur in the context in which it is experienced. Some participants spoke of being loved and cared for by family and friends, the care and concern of the transplant team, transplant anniversaries (i.e., re-birthdays), and/or the celebrations they had enjoyed since receiving a transplant. In the midst of this love, care, happiness or joy, the experience of gratitude had a highly positive valence. At other times participants spoke of feeling guilty about aspects of their transplantation experience. For example: receiving an organ from someone (they assumed to be) very young; or receiving an organ at the expense of someone (who might be considered) more worthy or deserving of the organ. At yet other times, they spoke of dissatisfaction, financial difficulties, unresolved health problems, and/or new health issues. Although they remained grateful for their organ transplant, the positive valence of the gratitude experience was attenuated in the milieu of these other emotions.

### 8.6 Alternative transplant discourses

Gift-of-life discourse marginalises the voices of those who are anything less than straightforwardly grateful for their transplant. These voices may be those of the most uncertain and vulnerable of transplant recipients. Their silencing can be powerfully
consequential for the ways in which they make meaning of their transplant experience and, ultimately, their ongoing physical and psychological health.

The narratives of some participants were not marked by gratitude but, instead, by emotions such as shame and anger. These emotions appeared to be driven by some of the devastating effects of transplantation, such as the inability to work or find employment, the financial difficulties that ensued from this, and the effects of these difficulties on the lives of recipients and their families. As Sharp (2006) emphasised: “biomedicine privileges knowledge concerned with the body’s biomechanics, often to the exclusion of both the inner workings of the self, or emotions, and the individual’s place within large social or ecological milieus” (p. 43). Sanctioned ways of encountering and speaking about transplantation exist, and particular narratives must be adopted. The voicing of aspects of transplantation that do not conform to gift-of-life discourse represents a social taboo. There is thus little leeway for the contingencies of recipients’ lives, and the emotions elicited by them, to be acknowledged and lived with.

Hope was the dominant discourse of those receiving dialysis. Dialysis, particularly long-term dialysis, can be a debilitating experience. Participants spoke of life on dialysis as one of many restrictions (dietary restrictions, physical restrictions, time restrictions, as well as social and relationship restrictions). Hope represents the life-blood of spheres of biomedicine such as transplantation, where the particular technology concerned represents potential for a future, or a much-improved quality of life.

8.7 Implications of this research

The narratives of transplant recipients and prospective recipients are an important source of information about the transplantation experience. There is wisdom inherent in patients’
illness stories, and access to this wisdom leads to a more complete understanding of the illness experience. Findings from this research may help to fill gaps in the knowledge base concerning transplantation, and also that of gratitude. This has important implications for the sensitive treatment of those with organ disease/failure, particularly the development of pre- and post-transplant interventions that facilitate better coping and adjustment.

Gift-of-life discourse largely prescribes and directs the experience of transplantation (Shaw, 2012; Shaw et al., 2012; Sothern & Dickinson, 2011). However, I found that many participants did not understand transplantation to be the gift-of-life, and expectations that they conform to the prescribed experience outlined by gift-of-life rhetoric are not without consequence. I also found that the experiences of heart transplantation, liver transplantation and kidney transplantation differ in ways that are powerfully consequential for the lives of the individuals concerned. A generic (gift-of-life) model of transplantation, generated from within the healthism paradigm, is rigid and does not allow for the recognition, acknowledgement and deep understanding of the realities of transplantation for those within the individual (i.e., heart, liver, kidney) organ groups. The voices of ‘good’ recipients (Sharp, 2006; Sothern & Dickinson, 2011) are heard: ‘good’ recipients cannot be ungrateful (or express anything other than unmitigated gratitude) in view of the magnitude of the gift. The voices of those who wish to speak out about the negative aspects and debilitating consequences of transplantation are silenced.

This study highlights the need for ongoing research to further clarify the understandings of transplantation that hold meaning for those concerned, the psychosocial issues most often encountered by those within different transplant groups, and the range
of emotions elicited in these differing contexts. A clearer understanding of how
individuals adjust to illness and its treatment offers important insights that may help to
enhance the efficacy of interventions that facilitate psychological adjustment (Sharpe &
Curran, 2006). Further research should broaden and diversify the samples studied (to
include, among others, those with different cultural and ethnic backgrounds), and include
a longitudinal and/or prospective focus. Knowledge of, and receptivity to, the
contingencies that can result in poorer treatment outcomes can be utilised to inform
clinical treatment, as well as guide healthcare professionals in their care of transplant
recipients and prospective recipients. This knowledge can also lead to the design and
development of interventions specifically targeted to meet the needs of recipients and
prospective recipients, and thereby enhance the physical and psychological health and
well-being of those concerned.

The study of gratitude in the context of transplantation has highlighted the finely
nuanced nature of this construct. Much literature attests to the complex and
multidimensional nature of gratitude (Emmons & Crumpler, 2000; McCullough et al.,
2002; McCullough et al., 2001; McCullough & Tsang, 2004). Within this body of
research, though, gratitude is most often assumed to be a relatively static phenomenon, in
the sense that it is experienced positively and is unchanging in this regard. I found that
although gratitude is a positive emotion, in the context of transplantation the experience
of gratitude is far from static.

McCullough et al.’s (2001) model of gratitude indicates that it is typically
experienced when four conditions are met. As outlined previously, these are: when a
benefit of value is received; the benefit is intentionally (rather than incidentally) given to
the individual concerned; the benefit involves some cost or effort on the part of the benefactor; and the benefit is given gratuitously. These conditions were ostensibly met for all of the participants of this study in their receipt of life-saving treatment for end-stage organ disease. However, only some participants reported experiencing gratitude in relation to their transplant and/or associated treatment, and the reported experiences of gratitude varied widely. This suggests that the context in which a benefit is given/received might play an important role in whether or not gratitude is experienced, the extent to which it is experienced, and how (e.g., more or less positively) it is experienced.

Individuals who are healthy and those who are ill do not experience hope in the same way and, consequently, a single model of hope cannot be applied uniformly across all contexts (Kim et al., 2006). Perhaps gratitude, like hope, is also experienced differently in the contexts of health and illness. This raises some interesting questions for further exploration. Is there something about illness, particularly chronic illness, which might influence the experience of gratitude? (For example, are chronically ill individuals less inclined to make downward counterfactuals than healthy individuals?) Is there something about the healthcare setting, specifically, that influences gratitude? (For example, does the extent to which treatment is understood to be an ‘entitlement’ of the healthcare system influence whether or not gratitude is experienced, and how it is experienced?) In view of answers to these questions, it might be relevant to propose a more dynamic model of gratitude: one that accounts for the contextualised nature of this complex construct.

Transplantation is a challenging experience for those who must endure this treatment for end-stage organ disease. It is a turbulent experience that may be likened to
an emotional rollercoaster: with low-lows, high-highs, and many twists and turns in between. Research has indicated that gratitude facilitates coping and adjustment (Fredrickson et al., 2003; Teigen & Jensen, 2011; Vernon et al., 2009; Watkins et al., 2004; Watkins et al., 2008; Wood, Maltby, Stewart, & Joseph, 2008), and post-traumatic growth (Linley & Joseph, 2004; Ruini & Vescovelli, 2013; Wood et al., 2010). Further research investigating the extent to which gratitude might represent a protective factor against the psychological distress of transplantation is warranted. Gratitude-based interventions aimed at teaching the cognitive strategies (e.g., benefit-finding and positive re-framing) that promote coping and adjustment might be useful in this context. Research directed toward the testing of existing gratitude interventions in the context of transplantation, as well as the design and development of innovative interventions, would be worthwhile.

The current study also goes some way toward addressing the paucity of gratitude research using a qualitative method. Qualitative approaches provide an avenue for accessing different kinds of knowledge: insights into lived experiences and the meanings made of these experiences. Attempts to generalise from these insights need to be made with caution. As noted by Brocki and Wearden (2006), though, this does not mean that an IPA analysis is “merely the retelling of respondents’ accounts” (p. 96). Analysis may be conducted in view of existing theories and models, and identified themes can have applicability (i.e., theoretical transferability) in other, similar, situations, and also in other research and clinical settings.
8.8 Limitations of the study

8.8.1 Unheard voices

This study includes the voices of some of those who have experienced transplantation. Selection bias is likely to have occurred, with particular voices (those of the relatively healthy) more likely to be included than those who were not faring so well. I was provided with lists of potential participants by nurse practitioners; these lists were drawn from the wider pool of transplant recipients and waitlisted prospective recipients who were patients at the respective hospitals and included only those patients deemed by the nurse practitioners to be healthy enough to participate. Also, not all of those who were invited to participate chose to do so, and there may well be important differences in the experiences of these people compared to those who did participate. Organ recipients, or those on the waiting list, who were not faring well, either physically or emotionally, might have different stories of transplantation to tell.

Western Australia is a large state (covering some 2,500,000 km$^2$) within a large country. Letters of invitation to participate were mailed to recipients across the state: the nurse practitioners thought that as patients return to the hospital for regular checks, some might have appointments that coincided with the interview period, and would thus be able to participate. However, it was less likely that those in remote communities would have the opportunity to participate. The experience of transplantation for those residing in these communities, with reduced access to medical care and support, might be different in meaningful ways to those in metropolitan communities. Many Indigenous Australians reside in these remote communities, and the differences in their cultural background might render their experience and understanding of transplantation different to those of
European Australians. (One Aboriginal man, a prospective kidney recipient who was living in the metropolitan area in order to more easily attend hospital appointments, participated in this study).

As I listened to recipients and prospective recipients, I was struck by how often they talked of their experience as a shared experience. Many participants spoke of “us” and “we” throughout their narratives. Many decisions were made as joint decisions. When Bill (prospective kidney recipient), for example, was offered a kidney that was potentially infected with the HIV virus, he reported telling the doctor who had phoned him that he had “reservations” about accepting it, and wanted to talk it over with his wife before making a decision. Later, referring to his wife and himself, he said: “so we said no [to the kidney offered]”. There were many such instances throughout the interviews. The lives of these others are clearly influenced by the illness of their loved one: they, too, are affected by the many struggles of the transplant experience. Knowledge and understanding of transplantation would be furthered with attention to the voices of these unheard others.

8.9 Self-reflection

The reflexive process in which I engaged across the time of this study was a period of intense learning for me, both academically and personally. I became more aware of the extent to which social and cultural biases inform our thinking and the way in which we relate to others and the society in which we live. This idea is far from novel; indeed it forms the cornerstone of social psychology theory. However, at the outset of this study I, somewhat naively, believed that I could set aside any preconceived ideas I held about the experience of transplantation, and the experience of gratitude in this context.
Through my initial reading of the transplant literature, I was aware of the hardships that transplant recipients and prospective recipients must endure. However, I quickly came to realise that reading about transplantation and sitting with transplant recipients/prospective recipients listening to them speak about their lives and the realities of organ failure and transplantation involves ‘understanding’ at two distinctly different levels. As I listened to the interview recordings and read the transcripts, I realised that during the early interviews I was expecting to hear some expression of gratitude (regardless of the hardships endured). I became intrigued by participants’ responses to ‘the gratitude question’ (i.e., if you think about your life as it is today, is there anything for which you are thankful or grateful?). Some participants were enthusiastic in their response, and these gratitude stories were easy to hear. Perhaps this was because they aligned so clearly with my (early) expectations of gratitude in this context. Other participants were more tentative in their approach to the question: they asked for clarification (Was I asking if they were grateful for their heart/liver/kidney? Was I asking if they were grateful to the donor? What, exactly, did I mean?). After contemplating the question for a while, these participants appeared to be comfortable with the idea of gratitude in relation to their treatment and/or their life in general, and these gratitude stories also tended to be easy to hear. Other participants, though, appeared perplexed (and some, even angered) by the question. I had not anticipated this response and these stories were more difficult to understand. If these participants were perplexed by ‘the gratitude question’, in the initial stages of the study I was equally perplexed by their responses.

Reflexive research practice is critical to effective interpretative phenomenological analysis. I spent many hours re-listening to participants’ interviews and re-reading the
transcripts. I also returned to the literature, going beyond the gratitude and transplant literature (to that concerning shame and hope, for example). Throughout this process, I continuously acknowledged my thoughts and feelings in relation to participants, their accounts of transplantation, and the literature. This reflexive practice contributed to an enhanced understanding of participants and their experiences, as well as the processes of interviewing, data collection, and analysis.

My personal experience of nursing my husband through terminal cancer meant that I could empathise with participants and many aspects of their lives. I believe this enabled me to engage with them at a level of deep understanding. Many participants said they felt comfortable speaking with me: some actively sought to extend the interview as it was coming to a close (e.g., by telling me about something that “[I] might find interesting for [my] study”); and others continued to engage in conversation after the recording device was turned off. Some broached challenging topics such as death and dying, or the ‘badness’ of wishing (indirectly) for someone else’s death. Others entrusted me with highly personal and intimate details of their lives such as relationship difficulties and sexual dysfunction. I believe the level of connection I experienced with many participants lead to the collection of rich data. Throughout the duration of the study, I continually reflected on my interpretation of the data, and I discussed it with my primary supervisor across many meetings to ensure that it was grounded in the data.

It was not possible for me to be part of this research and remain unaffected by it. As I listened to the recordings of transplant recipients and prospective recipients speaking about their lives (of ‘victories’ small and large, additional years, and the joys those years have brought with them, as well as many years of treatment, ongoing struggle with the
effects of immunosuppressant regimes, financial hardships and relationship difficulties), I became all the more aware of the blessings of my own life.

8.10 Conclusion

Living in defiance of death, life for transplant recipients and prospective recipients is forever caste in the shadow of this life-saving biotechnology. ‘Health’ and ‘normality’ become highly contingent states for those concerned (Crowley-Matoka, 2005). New, dynamic, models of care are needed for chronic illness, particularly those involving biotechnologies where sense of self and being-in-the-world are compromised. These new models must pay heed to the situatedness and contingencies of lives, in order to best meet the needs of those requiring treatment. In reference to bioethical discourse and practice, Walker (2009) reminds us that: “societal conversations are not open circuits in which all have a chance to be heard under conditions of comparable respect and credibility” (p. 3). We can learn much about illness, treatment, and the consequences of both, from the ill themselves, and Frank (1995) has utilised the term ‘pedagogy of suffering’ to describe what the ill have to teach society. In the realm of transplantation, the stories of transplant recipients and prospective recipients reveal much about the intersection of individual lives, biomedical technologies and cultural discourses. The transplant community and all those invested in understanding and caring for those with end-stage organ disease are well served by listening to them.
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Appendix A

10.1 Schedule of Interview Questions

Potential Recipients: Pre-Transplant

1. Can you tell me something about the circumstances that led to you being placed on the transplant waitlist?

2. Can you describe your thoughts and feelings when you were told that you needed to receive a (name organ)?

3. Can you tell me something about your current situation: how you presently think and feel about waiting for a (name organ)?

4. Is there anything in your life right now for which you are thankful/grateful? If so, can you tell me about these things?

5. Can you describe the difference/s that you believe a new (name organ) will make to your life?

6. In the media, transplantation is often talked about as a ‘gift’ or the ‘gift of life’. Can you tell me about your thoughts and feelings in relation to this?

Recipients: Post-Transplant

1. Can you tell me something about your thoughts and feelings when you were told that you would be receiving a (name organ)?

2. It is now (length of time) since you received your (name organ). Can you tell me about the changes that have taken place in your life in that time?

3. Please reflect on the differences that you thought a new (name organ) would make to your life. Can you tell me about the ways in which the transplant has/has not met your expectations?
4. Is there anything in your life right now for which you are thankful/grateful? If so, can you tell me about these things?

5. Can you describe your thoughts and feelings in relation to your new (name organ)?

6. In the media, transplantation is often talked about as a ‘gift’ or the ‘gift of life’. Can you tell me about your thoughts and feelings in relation to this?

7. The experience of gratitude may go hand-in-hand with feelings of obligation and indebtedness. Have you experienced these, or similar, emotions in relation to your transplant? If so, can you describe this experience to me?

8. Can you tell me something about how you think your life may be over the next six months?
Appendix B

10.2 Ethics Approval Numbers

Murdoch University Human Research Ethics Committee: 2009/240

Royal Perth Hospital Human Research Ethics Committee: 2010/031

Sir Charles Gairdner Hospital Human Research Ethics Committee: 2010-143