Quality of Life and Organ Transplantation: Patient, Family, and Health Professional Perspectives on a Second Chance at Life

A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Psychology

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Declaration of Authorship

I, Bianca Denny, certify that, except where due acknowledgement has been made; the work is that of the author alone. The work has not been submitted previously, in whole or in part, to qualify for any other academic award. The content of the thesis is the result of work which has been carried out since the official commencement date of the approved research program. Any editorial work, paid or unpaid, carried out by a third party is acknowledged and, ethics procedures and guidelines have been followed.

Signed: _________________________
Name: Bianca Denny
Date: _________________________
Acknowledgments

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Dissemination Information

Sections of this thesis have been disseminated as publications and conference presentations. The references for these are detailed below:


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### Glossary of Terms

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<th>Acronym</th>
<th>Full term</th>
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<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>AODR</td>
<td>Australian Organ Donor Registry</td>
</tr>
<tr>
<td>CLARA</td>
<td>Clinical Lookup and Results Acknowledgement</td>
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<tr>
<td>CTA</td>
<td>Composite Tissue Allotransplantation</td>
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<tr>
<td>DPMP</td>
<td>Donors Per Million Population</td>
</tr>
<tr>
<td>ESLD</td>
<td>End Stage Liver Disease</td>
</tr>
<tr>
<td>FAQ</td>
<td>Family Accommodations Questionnaire</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HREC</td>
<td>Human Research Ethics Committee</td>
</tr>
<tr>
<td>MANOVA</td>
<td>Multivariate Analysis of Variance</td>
</tr>
<tr>
<td>MMC</td>
<td>Monash Medical Centre</td>
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<tr>
<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>PTSD</td>
<td>Posttraumatic Stress Disorder</td>
</tr>
<tr>
<td>PSS</td>
<td>Perceived Stress Scale</td>
</tr>
<tr>
<td>RCH</td>
<td>Royal Children’s Hospital</td>
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<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>TPB</td>
<td>Theory of Planned Behaviour</td>
</tr>
<tr>
<td>TPPSS</td>
<td>Transplant Patients’ Perceived Stress Scale</td>
</tr>
<tr>
<td>TRSS</td>
<td>Transplant-Related Stressors Scale</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
</tr>
<tr>
<td>VABS</td>
<td>Vineland Adaptive Behaviour Scale</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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</table>
Abstract

Organ transplantation is a procedure that has the potential to extend the life expectancy of people experiencing end-stage organ failure. First pioneered in the 1960s, surgical procedures and immunosuppressive technologies have now been refined to a level at which long-term survival after organ transplantation is the norm rather than the exception. As such, researchers and medical practitioners alike have moved away from measuring the success of transplantation purely by patient survival. Rather, patient quality of life (QOL) has become a widely accepted criterion by which to measure achievement in the field of organ transplantation.

Quality of life refers to an individual’s subjective experience of functioning in the domains of physical, psychological, and social wellbeing. The QOL of transplant patients has been widely researched, and there is general agreement that transplantation is associated with QOL benefits, with transplant recipients enjoying a better QOL than transplant candidates. However, despite burgeoning academic interest in this area, several conceptual and empirical aspects of QOL within the field of organ transplantation have not yet received adequate attention. First, no previous research has attempted to explain ubiquitous QOL findings from a theoretical perspective, resulting in a significant deficit of knowledge in this much-researched area. Second, most research has focused on QOL experiences purely from the perspective of transplant patients, with little consideration of the way in which patients’ QOL issues are perceived by health professionals. Last, while the QOL of pediatric transplant patients is covered extensively within the literature, little sustained attention has been paid to the relevance of young patients’ families and the home environment in the context of QOL.
The present thesis is comprised of three separate studies, which together aim to present a holistic exploration of the QOL of organ transplant patients. *Chapter 1* provides an introduction to the field of organ transplantation. The conceptual and theoretical background to QOL is detailed, and its application and relevance to organ transplantation is explained. The three studies encompassed in this thesis are briefly introduced, together with the rationale and aims for each.

Study 1, entitled ‘Using crisis theory to explain the quality of life of organ transplant patients’, is contained in *Chapter 2*. The aim of this study was to explore the QOL of organ transplant patients from a theoretical perspective. Crisis theory was used to investigate the relationship between stress, coping, and QOL. A total of 226 participants representing non-transplant individuals, transplant candidates, and transplant recipients participated in the study, providing insights into the unique experiences of transplant patients and enabling comparisons of each group’s QOL and functioning in the specific domains of physical, psychological, and social wellbeing. Results supported the premise of crisis theory, with findings showing that transplant candidates experience lower QOL than transplant recipients and non-transplant individuals. Further, specific transplant-related stressors identified as worrisome by transplant patients were explored and discussed.

Health professionals’ perspectives on transplant patients’ QOL issues is investigated in Study 2, and is presented in *Chapter 3*. This exploratory study examined QOL from the perspective of people who work with transplant patients, and sought to investigate the dissemination of copious amounts of QOL research, information, and data to clinical practice. The views of 41 health professionals on QOL were explored using an adapted questionnaire previously used within oncology research. Information elicited included health professionals’ attitudes toward the
concept of QOL, reported willingness to use QOL instruments and information, and actual use of QOL information in clinical practice. Results revealed inconsistencies between health professionals’ attitudes, willingness, and behaviour associated with QOL. Several suggestions are made to increase the use of QOL information in clinical practice, with a recommendation for future research to further explore the way in which health professionals’ views may impact upon the QOL of transplant patients.

Study 3, contained within Chapter 4, investigated the QOL experiences of 32 pediatric liver transplant patients. Together with comparing the QOL of young transplant patients with 33 non-transplant children in the community, the study sought to investigate the way in which families adjust to accommodate children who have received liver transplants. The relationship between family functioning and QOL was also explored, with results showing an association between decreased QOL and increased adjustments to family routines. The finding that transplant families make more adjustments to routines to accommodate their children in comparison to other families informed several recommendations to ease the burden on transplant families and, in turn, enrich the QOL of pediatric liver transplant patients.

A general discussion is offered in Chapter 5, including conclusions drawn from the thesis as a whole, strengths and limitations, methodological issues, and suggestions for future research. Theoretical implications of the findings are presented, together with suggestions for the implementation of practical applications that may optimise the QOL of organ transplant patients. The synthesis of findings presented across the three studies informs a strong rationale for the continued expansion of QOL research within the field of organ transplantation. Findings indicate a need for research to move beyond assessing QOL solely from the perspective of patients. The outcomes of these preliminary studies involving health professionals and families
point to the importance of understanding the context in which QOL is experienced by organ transplant patients. Varied investigation is required to achieve a full understanding of QOL in the context of organ transplantation, thus enabling all patients to enjoy the full QOL benefits afforded by transplantation.
Chapter 1

Organ Transplantation and Quality of Life

Individuals experiencing end-stage organ failure undergo organ transplantation in order to extend life expectancy. In addition to the clear benefit of reducing mortality rates among patients with end-stage organ failure, research has consistently shown that receiving an organ transplant also results in substantial improvement to quality of life (QOL) (Dew et al., 1997). Despite extensive research dedicated to this area and ubiquitous findings of the QOL benefits associated with organ transplantation, there remain significant gaps in the theoretical and applied knowledge of QOL in this field. There has been a distinct shift in academic attention away from the medical success of organ transplantation to the study of its psychosocial aspects over the past few decades, and researchers are now calling for a further move beyond descriptive and comparative studies of organ transplant patients’ QOL to theoretically driven investigations that may inform intervention and treatment to assist transplant patients to achieve lives of good quality (Engle, 2001; Myaskovsky et al., 2005; Wood-Dauphinee, 1999).

This chapter provides a foundation for the study of QOL in the field of organ transplantation. First, information pertaining to the historical developmental of the life-saving procedure will be presented, together with a brief overview of the medical aspects central to its ongoing success. Second, the concept of QOL will be detailed through a summary of its theoretical underpinnings and an overview of the numerous fields and ways in which QOL has been studied. Moving forwards, a rationale for the study of QOL in the context of organ transplantation will be presented, together with an argument for the need to significantly expand the limited scope of current QOL
research in this area. Last, the aims of the three studies contained within this thesis are introduced, with each offering a unique perspective on the QOL of transplant patients.

**Organ Transplantation**

The idea of transferring body parts has long been expressed as fantasy in art and literature. Greek mythology featured centaurs that were half-man and half-horse, ancient Egyptians celebrated the Sphinx, and the Hindu deity Ganesha had a human body and an elephant’s head. The replacement and repair of body parts also featured in the Bible, with Christ restoring the ear of a servant after it had been cut off with a sword. In the fifteenth century, Saint Agatha was depicted with reconstructed breasts, and the patron saints of doctors, Saints Cosmos and Damian, were illustrated transplanting the limb of a deceased donor to a patient afflicted with a tumour of the leg. Literature also embraced the theme of transplantation, with Mary Shelley’s Frankenstein character creating a monster patched together from body parts collected from graveyards and slaughterhouses (Calne, 1970; Magee, 2004; Tilney, 2003).

Several of the fantastical ideas expressed throughout history are now an everyday part of modern medicine. Organ transplantation has been brought into reality by years of experimental research and immense scientific advances in medical procedures and pharmacology. Transplantation procedures evolved relatively quickly from experimental stages marked by limited success to its current prosperous state. Experiments on dogs, rodents, and monkeys from the early 1900s to 1970s refined the procedures of kidney, liver, and heart transplantation, and canine skin grafts and animal blood transfusions were also conducted. Human organ transplantation in its current endeavour began in the 1950s, with the first successful kidney transplant between young identical twins in 1954. Adult lung and heart transplantations followed in 1963 and 1967, respectively. However, initial transplantation efforts had
limited success, with patients surviving for only short periods of days or weeks following surgery. Early transplantation efforts failed largely due to a lack of knowledge and misunderstanding of blood types, tissue matching, and the role of immunosuppressant medication in avoiding organ rejection (Engle, 2001).

The discovery of the powerful immunosuppressant, Cyclosporine, ushered in a new era of successful solid organ transplantation. Prior to its introduction, patients were routinely treated with total-body radiation. While radiation treatment resulted in patients producing fewer antibodies towards the transplanted organ and provided an amount of protection against infection, increased awareness of the dangers of radiation led to a sharp decline in its use and renewed experimentation with immunosuppressive medication. Patient survival incrementally increased following the introduction of new immunosuppressant medication in 1959, and another medical breakthrough occurred with the 1962 discovery of tissue typing (Magee, 2004). Cyclosporine was first used in 1978 and approved for widespread use in 1983, revolutionising organ transplantation by limiting infection and subsequent organ rejection. The success of Cyclosporine brought about seminal change to both the clinical and research fields of organ transplantation; renewed interest in the procedure was accompanied by increased research activity, and the provision of clinical services increased rapidly with more surgeons and institutions performing transplant operations (Tilney, 2003).

An estimated 105,000 patients are currently on the national organ waitlist in the United States (US), with a new name added every 14 minutes. With 56,000 solid organ transplant procedures performed in the US annually, 11 Americans die each day before receiving a transplant (Wynn & Alexander, 2011). Australian statistics also show a divide between supply and demand of organs for transplantation, despite an
increase in transplant rates in recent years due to improved rates of posthumous donation. While 1599 individuals are currently awaiting transplantation, only 991 people underwent transplantation in Australia in 2011, meaning that some Australian organ transplant candidates are likely to die before receiving a suitable organ (Excell, Hee, & Russ, 2011). Table 1 provides a summary of the most common solid organ transplantation procedures, together with the historical context and survival rates related to each type of transplant. The vast majority of transplant candidates in Australia are awaiting a kidney transplant, followed by liver, lung, and heart transplants. A small number of Australian candidates are also awaiting intestinal and pancreas transplants, and a further few require heart/lung or pancreas/kidney double transplants (Excell, et al., 2011).

Organ transplantation is widely considered to be the best treatment option for end-stage organ failure. End-stage organ failure is a medical condition in which a person’s organs do not function adequately (Molzahn, Northcott, & Dossetor, 1997), and may be precipitated by emphysema and chronic obstructive pulmonary disease (lungs); cardiomyopathy and congestive heart failure (heart); hepatitis (liver); and polycystic kidney disease and chronic renal failure (kidneys). Illnesses that constitute end-stage organ failure can occur in people of any age and background. Individuals experiencing such disease are extremely unwell, and are generally unable to meet the demands of everyday life, cannot gain or keep employment, and require intensive treatment and care. The typical course of end-stage organ failure is marked by gradual decrease in daily functioning and acute deterioration in health, and patients typically experience pervasive symptoms of fatigue, breathing difficulties, insomnia, and chronic pain. End-stage organ failure is a terminal illness, and a fine line exists between the need for an organ transplant and palliative care (Janssen, Spruit, Wouters,
Patients usually undergo treatment while waiting for transplantation, including dialysis for kidney patients; respiratory treatment for lung patients; and anti-inflammatory medication for liver patients. However, these treatments are used to manage symptoms in the short-term, and are not long-term alternatives to transplantation (Janssen, et al., 2008).

Organ transplantation has the potential to rapidly restore the health and wellbeing of individuals experiencing end-stage organ failure. However, organ transplantation is not considered a cure for end-stage organ failure, but an alternative form of treatment that unfortunately presents ongoing medical and psychosocial challenges for transplant recipients (Engle, 2001). With this in mind, all potential transplant candidates undergo medical and psychosocial evaluation before being added to the national waitlist to receive a transplant. In some countries an economic assessment is also conducted, but in Australia and most Western countries the estimated $200 000 cost of transplantation is covered by public health policy. However, pre- and post-transplant monthly medication costs of up to $3000 are only partially covered (Hafliger, 2005). Candidacy assessments aid in the identification and management of patients who meet criteria consistent with a reasonable probability for a favourable surgical outcome, and provide baseline measures that can be used for medical or psychosocial intervention should either be required at a later stage in the transplant process.

Medical assessments are used to evaluate current health and physical functioning. Contraindications to transplantation may also be identified during this process, including cancer in an organ other than the one being transplanted, human immunodeficiency virus (HIV), and chronic progressive neurological illness (Hafliger, 2005). Psychosocial assessment is usually conducted by a psychiatrist
<table>
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<th>Common precipitants to transplantation</th>
<th>First human transplant procedure</th>
<th>Average waitlist time</th>
<th>Australian waitlist 2011</th>
<th>Australians transplanted in 2010</th>
<th>Donor source</th>
<th>Survival rate</th>
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<tr>
<td>Kidney</td>
<td>Diabetes, Hypertension, Gomerulonephritis</td>
<td>1954</td>
<td>7 years</td>
<td>1223</td>
<td>842</td>
<td>Cadaver</td>
<td>97% 91%</td>
</tr>
<tr>
<td>Liver</td>
<td>Hepatitis C</td>
<td>1967</td>
<td>2-5 years</td>
<td>167</td>
<td>203</td>
<td>Cadaver</td>
<td>80-90% 80%</td>
</tr>
<tr>
<td>Lung</td>
<td>Cystic Fibrosis, Chronic Obstructive Pulmonary Disorder, Pulmonary Fibrosis</td>
<td>1963 (patient survived for 18 days)</td>
<td>1-2 years</td>
<td>110</td>
<td>123</td>
<td>Cadaver</td>
<td>75% 50%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>First double lung transplant in 1989.</td>
<td>1967 (patient died 18 days later from septicemia)</td>
<td></td>
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<tr>
<td>Heart</td>
<td>Cardiomyopathy</td>
<td>1967</td>
<td>&gt;1 year</td>
<td>46</td>
<td>65</td>
<td>Cadaver</td>
<td>90% 80%</td>
</tr>
</tbody>
</table>

*Note. Information sourced from Hafliger (2005) and Excell, et al. (2011).*
or other mental health clinician, and aims to assist in the selection of patients capable of handling the stress of transplantation, assess patients’ knowledge and capacity for consent, assess ability to comply with complex medical regimens, and determine the need for family support (Klapheke, 1999). The extensive interactions between patients and health professionals has been posited as an important contributing factor to QOL, and requires further attention in the field of organ transplantation (Bezjak et al., 2001). Psychosocial assessment is particularly important to the transplantation process, as patients require extensive social support and assistance. Given that potential candidates without family or partners capable or providing care are not usually accepted for transplantation (Hafliger, 2005; Olsbrich, 1996), further attention on the relationship between families and transplant patients’ QOL is also warranted.

Assessment may also inform recommendations for pre- and post-transplantation interventions designed to optimise patients’ candidacy and prevent morbidity and mortality. Waitlist priority and organ allocation is based on organ availability, organ size, donor and recipient biological compatibility, the degree of patient need, patients’ nearness to death, and time on waitlist (Olsbrich, 1996). The organ allocation system has received criticism, with Neuberger (2012) arguing the need for greater balance between the rights of the dying and those patients with an intolerable QOL, stating that patients with dire medical needs are given preference over patients who have good organ function but unacceptable QOL. While candidates may wait up to several years to receive an organ transplant, post-transplant recovery time is relatively brief, with most recipients able to return home from hospital within weeks and resume work within six months of transplantation (Hafliger, 2005).

Organs for transplantation are obtained from three potential sources, including brain-dead donors, non beating-heart donors, and living donation (Hafliger, 2005).
Posthumous organ donation in Australia is governed by an opt-in system, in which individuals indicate their intention to become an organ donor in the case of death via the Australian Organ Donor Registry (AODR). Final decisions regarding organ donation are made by next-of-kin, who are informed by medical personnel of the deceased person’s wishes according to the AODR (Excell, et al., 2011). The vast majority of organs transplanted are harvested from brain-dead donors. In this type of donation, brain functioning has completely ceased, and the donor has been certified legally dead by two independent medical doctors (Hafliger, 2005). The heart, kidneys, lungs, pancreas and intestines of brain-dead donors can be harvested, potentially benefitting up to seven transplant candidates. Non beating-heart donors are in persistent terminal, vegetative states or are already deceased. The discontinuation of life support induces cardiac arrest in non beating-heart patients, after which time the liver and kidneys may be harvested (Lopez-Navidad, Domingo, & Viedma, 1997). Lastly, living donation involves a whole or part organ from a healthy person being removed and donated to a transplant candidate, and is currently possible for kidney, lung, and liver transplantation. Living donation was pioneered in the 1980s and is widely encouraged to offset the current relative deficit of cadaver organs. Living individuals can donate one of their two kidneys, or a section of lung or liver, with the liver regenerating itself to 80-90% of its original size within six to eight weeks. The procedure of organ removal is tolerated well by donors, with few postoperative complications and a low mortality rate of 0.4% (Cotler et al., 2003; Schiano, Kim-Schluger, Gondolesi, & Miller, 2001). Beyond the technical aspects of organ transplantation, extensive research has explored many aspects of transplantation, including medication, psychological wellbeing, and donation rates.
**Organ transplantation research.** Transplantation research is prolific, with dozens of journals dedicated to its progress and many other organ transplantation studies published in a variety of academic journals. The research covers many fields, including science, medicine, nursing, psychology, social science, and health economics. Common areas of research include immunosuppression, the psychological wellbeing of transplant patients, medication compliance, and organ donation rates. Studies assessing the QOL of transplant patients proliferated in the 1980s, with the increased survival rates brought about by Cyclosporine permitting researchers to turn attention to life quality in addition to longevity. However, the study of transplant patients’ QOL has been marred by several factors, including a lack of consideration of conceptual or theoretical models of QOL, and a tendency to reaffirm established QOL findings rather than focus on new areas of study. The study of QOL in organ transplantation will be covered in further detail in *Chapter 2*.

Prior to the advent of Cyclosporine, organ transplant research focused almost exclusively on surgical techniques and the development of immunosuppressant medications (Joralemon & Fujinaga, 1997). Much research is still dedicated to the continued development and refinement of the medical aspects of transplantation (Falger, Latal, et al., 2008; Hafliger, 2005; Otte, 2002). Continued efforts to improve immunosuppressant technology are designed to eradicate the incidence of organ rejection; transplants can be thought of as ‘borrowed’ organs, and the recipient’s body and immune system will always treat the transplanted organs as foreign tissue and will act to reject the transplant. Organ rejection has serious implications and is best prevented rather than cured, and as such transplant teams and surgeons employ careful donor-recipient matching as part of the thorough pre-transplant preparation process. Rejection episodes are difficult to treat, and may result in a relapse to end-
stage organ failure and a return to the waitlist for retransplantation. Further, patients who have experienced an organ rejection do not respond as well to alternate treatments such as dialysis (Engle, 2001).

In addition to the potential for organ rejection, morbidity and mortality rates among transplant patients are greatly impacted by medication compliance and adherence to medical advice. To this end, compliance is voluntary and transplant patients have an important and active role in avoiding infection and organ rejection. The rate of noncompliance among transplant patients has been described as unacceptably high, placing patients at increased risk of protracted illness and possible death (Dew et al., 2007). Research has focused on factors that affect adherence to medical advice and medication, with compliance found to be impacted by a variety of factors, including socio-demographic variables, the complexity of the immunosuppressive regimen, medication side-effects, time since transplantation, and psychosocial variables such as depression, anxiety, social relationships, and stress (Achille, Ouellette, Fournier, Vachon, & Hebert, 2006; Frazier, Davis-Ali, & Dahl, 1995; Griffin & Elkin, 2001). The ethical considerations associated with retransplantation is also an emerging area of research, with a call for clinical guidelines and decision-making structures surrounding the controversial issue of retransplanting patients in instances where organ failure was caused by non-adherence to treatment and medication (Dobbels, Hames, Ajuoulat, Heaton, & Samyn, 2012). Similarly, Neuberger (2012) called for clear systems to be in place to assess and respond to patient noncompliance.

The incidence of psychopathology among transplant patients has received a good amount of attention in the literature. Approximately 50% of all transplant candidates meet criteria for a psychiatric disorder, with most diagnosed with
adjustment disorder in the context of the incredibly stressful experience of the transplantation process (Olbrisch, Benedict, Ashe, & Levenson, 2002). Most transplant patients have some extent of neuropsychiatric impairment due to end-stage organ failure, with symptoms of cognitive impairment typified by concentration and memory problems. Kidney transplant candidates undergoing dialysis are at risk of depression, and renal failure is associated with neuropsychiatric problems, such as attention difficulties and the development of psychosis. Lung transplant candidates are also likely to experience anxiety and depression, and have an increased risk of developing panic disorder. One in five heart transplant candidates experience major depressive disorder, while one in four continue to experience depression following heart transplantation (Dew et al., 2001). Delirium is quite common in the postoperative phase for all transplant patients, with lung transplant candidates especially susceptible to experiencing delirium due to hypoxia (Hafliger, 2005; Klapheke, 1999).

Serious psychopathology may interfere with the transplantation process and has implications for patients’ morbidity and mortality. Schizophrenia, personality disorders, and major depression may be associated with self-care difficulties among patients and in some cases results in instances of self-harm and suicide (Olsbrich, 1996). Alcohol and substance abuse issues also need to be carefully considered, especially among liver transplant patients. Personality disorders are usually considered to be a contraindication to transplantation, as patients generally have poor coping skills that place them at a higher risk of psychiatric morbidity following transplantation, and the manipulative tendencies and impulsive behaviour common to individuals with personality disorders generally disrupts the transplantation process. Further, excessive need for reassurance and overreliance on professional and personal
support systems may lead to rapid and intense transference reactions, which, in turn, can evoke countertransference among members of the transplant team. Individuals experiencing active psychosis are also usually considered unsuitable for transplantation; however, successful transplantation in psychotic patients can be achieved with careful medication management and suitable professional and personal support. Mood disorders must also be carefully monitored among transplant patients, as depressive episodes can have a detrimental impact upon motivation to adhere to treatment and attend medical appointments (Klapheke, 1999). Rejecting candidates for transplantation based on personality features or psychiatric wellbeing has repercussions for the ethical decision making of transplant teams, and as such literature on the ethics of transplantation has received increased attention in recent years (Cotler, et al., 2003; Kaufman, Shemesh, & Benton, 2010; Olbrisch, et al., 2002).

Transplantation also has implications for the prescription and dosage of psychotropic drugs and other medications used to treat common psychological disorders such as depression and anxiety. End-stage organ failure and immunosuppressant medications are associated with changes to transplant patients’ blood flow, medication uptake, excretion of medication, and metabolism. Steroidal immunosuppressant medication can induce mania, and therefore candidates who experience depression should be monitored for labile mood and irritability after transplantation (Hafliger, 2005). Given such possible complications and the probability of adverse reactions, the prescription of psychiatric medication to organ transplant patients requires careful assessment and comprehensive, ongoing management from a psychiatrist (Klapheke, 1999).
Lastly, organ donation rates and decision-making related to becoming an organ donor have attracted much academic attention. The worldwide shortage of organs for transplantation results in the death of thousands of people with end-stage organ failure each year, and the uncertainty of receiving an organ has been posited as contributing to the development of psychological problems among transplant candidates (Engle, 2001). Current organ donation rates in Australia are among the lowest in the developed world, with 13.8 donors per million population (DPMP) substantially lower than that of the US rate of 25.6 DPMP and Portugal’s rate of 30.4 DPMP (Excell, et al., 2011). Research has shown that organ donation rates in Australia have been affected by hospital-based problems such as poor identification of potential organ donors, shortage of intensive care beds, and non-prioritisation of donor cases (Mathew, 2004). Further research has investigated factors affecting individuals’ willingness to register as posthumous organ donors, including knowledge of the transplantation process, attitudes towards transplantation, religiosity, perceived beliefs of family and friends toward organ donation, and fear of death (Hyde & White, 2007; Minniefield, Yang, & Muti, 2001; Sanner, 1994). Such research has important implications for QOL research, as increased wait time and uncertainty around receiving a transplant is associated with low QOL among transplant patients (Barr et al., 2003; Zipfel et al., 1998).

**Quality of Life**

The pursuit of a life of good quality is a hallmark of human civilisation. As such, a vast amount of academic attention has been dedicated to the study of QOL and its conceptualisation and measurement. The construct of QOL offers an organised framework for investigating and describing people’s lives and experiences (King, 2012). Quality of life has been investigated in many contexts and settings, including
politics, education, sociological studies, advertising, healthcare, oncology, and disability. An evaluation of patients’ QOL is now included as an outcome measure in many clinical trials, and QOL has also been the central focus of extensive research in a variety of healthcare settings. The QOL of patients has long been central to research in the field of organ transplantation, with increased interest in the topic following the resolution of many difficulties associated with the medical and pharmacological aspects of the transplantation procedure.

The philosopher Aristotle was among the first to write of the concept of QOL, remarking that the quality of a person’s life is determined by its activities (Roop, Payne, & Hazard Vallerand, 2012). More recently, the term QOL entered popular vernacular through US socio-economic research in the 1950s in which it was defined in terms of employment, housing, and income. Around this time, medicine also began to counterbalance its traditional role of extending quantity of life with attempts to also improve the quality of patients’ lives. Heralding the move from ‘mechanistic medicine’ to ‘humanistic medicine’ in the 1960s, British physician Sir Robert Platt lectured on the need for doctors to enquire about patients’ life satisfaction. The concept of QOL slowly gained increased attention during the 1970s, and the 1980s marked widespread awareness of QOL (Basu, 2004). More importantly, the World Health Organisation’s (WHO) initial and enduring definition of health laid the foundation for the conceptualisation of QOL and future research in the field, with WHO’s 1948 definition of health as a state of complete physical, mental, and social wellbeing moving well beyond early interpretations that focused purely on health and physical functioning (Orley & Kuyken, 1994). Health and QOL quickly became central to debates on a variety of issues, including the role of national parks in promoting health and wellbeing, international development plans, immigration, and
ethically acceptable medical treatment for incapacitated and comatose patients (Engle, 2001).

It may be argued that the increased attention afforded to QOL across many areas of study is a direct result of vast improvements to life expectancy, with life expectancy in Western countries rising from 49.2 to 77 years over the past 30 years. Further, today’s population generally live with a sequela of injury or chronic illness for several years before death, contrasting the experiences of previous generations who generally succumbed quickly to death following an acute illness. Increased life expectancy has been brought about by factors such as public health campaigns, rising standards of living, improved sanitation, eradication and control of communicable diseases, and new medical therapies (Joralemon & Fujinaga, 1997; Roop, et al., 2012).

The study of QOL has been lauded for its salutogenic focus. Its attention to positive adaptation and resolution of stress aimed at improving the wellbeing of transplant patients is a contrast to deficit models that concentrate on pathology and illness (Albrecht & Devlieger, 1999). While the focus on resilience and wellbeing is reminiscent of the stance of positive psychology, studying QOL also has important practical implications, including informing interventions designed to maximise life quality. Thorough consideration of QOL also yields a more complete picture of the nature of health and disease by linking QOL to life expectancy and longevity, thus promoting a holistic approach to healthcare. Orley and Kuyken (1994) contend that raised awareness of QOL issues among health professionals results in more meaningful and fulfilling interactions with patients and more comprehensive patient care; this will be explored in Chapter 3 of this thesis. On a broader level, QOL research informs national and international public health policy by allowing
comparisons beyond cost and survival rates, and provides guidance at micro and macro levels of health economics to ensure limited financial resources are allocated in the best possible manner (Fox-Rushby, 1994).

While the benefits of QOL research are widely accepted, psychosocial research in the field of organ transplantation has thus far been limited. The research has lacked a theoretical basis, with little academic attention afforded to the conceptual nature of transplant patients’ QOL. Bean and Wagner (1996) used a model of self-transcendence to account for liver transplant patients’ positive QOL; others have used the Roy Adaptation Model (Lefaiver, Keough, Letizia, & Lanuza, 2007) and the Orem nursing theory to explore the impact of caregivers on transplant patients’ QOL (Norris, 1991). Crisis theory may also be used to explore transplant patients’ QOL (Moos & Schaefer, 1986).

Further, the focus on transplant patients’ perspectives has led to a lack of consideration of the way in which other factors, including health professionals and families, contribute to QOL outcomes following transplantation. The agenda for transplant QOL research has changed little since its initial proliferation in the 1980s, and must expand its focus in order to contribute meaningful information to the understanding of the lives of transplant patients.

**Definition of quality of life.** The concept of QOL has been embraced by various disciplines across the social sciences, medicine, and economics. Each discipline has fostered its own distinct understanding of QOL, with the social sciences largely rejecting medicine’s focus on physical health and instead embracing humanistic notions of normalisation, social role valourisation, and empowerment (Cummins, 2005). Despite these differences, there is general agreement on the conceptualisation of QOL as a construct that has several core elements. It is
multidimensional, and comprised of both objective and subjective components. It is a universal measure containing the same components for all people, and is influenced by personal and background factors and the interaction between individuals and their environment. Lastly, self-determination, resources, purpose in life, and a sense of belonging enhance QOL.

In keeping with WHO’s definition of health, QOL is considered to be more than the absence of disease (Burra & De Bona, 2007; Cummins, 2005). Indeed, WHO provide the most widely used definition of QOL, stating that it is “an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns” (Orley & Kuyken, 1994, p. 43). The broad-ranging concept incorporates physical health, psychological state, level of independence, social relationships, personal beliefs, and a person’s relationship to salient features of their environment (Orley & Kuyken, 1994). Albrecht and Devlieger (1999) offer a more simplistic view of QOL, stating that a good QOL implies being in good health and experiencing subjective wellbeing and life satisfaction.

**Assessment of quality of life.** Awareness of the concept of QOL has been accompanied by interest in the measurement of QOL. The purpose of measuring QOL is to provide accurate assessments of individuals’ wellbeing, and is most usually measured in the context of healthcare. The most widely used application of QOL measures is in clinical trials, with the concept less often measured in routine clinical care or medical audits. Both disease-specific and generic measures of QOL have been developed, with WHO’s continued QOL research integral to the development and validation of measures across cultures and populations (Orley & Kuyken, 1994). In addition to considering the multidimensional nature of QOL, measures must also meet
requirements of reliability and validity, and be appropriate and practical for the population or health problem being investigated (Basu, 2004). The measurement of QOL in relation to organ transplantation will be discussed further in Chapter 3.

**Theoretical model of quality of life.** Figure 1 presents a conceptualisation of QOL that integrates the essential components of the definition of QOL. Felce (1997) theorised QOL to be an expression of general wellbeing comprising objective descriptors and subjective evaluations of physical, psychological, and social health, all weighted by a personal set of values. The model consists of three major components: objective life conditions, subjective feeling of wellbeing, and personal values and aspirations. The model represents WHO’s definition of QOL through the inclusion of physical, psychological, and social functioning, and the subjective nature of QOL is also considered. According to the model, the three components are interdependent and have the potential to interact and impact upon QOL.

Life conditions refer to the objective description of individuals and their circumstances. The objective conditions in which an individual or group live may be observed or measured by comparing their position to the total population distribution in any given area. Living conditions may impact upon personal satisfaction, but do not necessarily define a person’s happiness and wellbeing. As such, objective standards cannot be used to reliably rate an individual’s QOL (Felce, 1997). There is an uncertain relationship between objective and subjective views of QOL, and a person’s perception of personal health, wellbeing, and life satisfaction are often discordant with their objective health status and physical functioning (Albrecht & Devlieger, 1999). For example, an individual with an income double that of their neighbour is not necessarily twice as satisfied with their earnings, and two individuals
with the same objective health status may potentially report widely divergent QOL (Burra & De Bona, 2007; Cummins, 2005).

*Figure 1. An overall model of quality of life. Adapted from Felce (1997)*
The subjective nature of QOL has long been recognised, with Mark Twain writing in 1902 that the value of life must be discerned from the individual’s perspective (Edgar, 1996). Subjectivity has been described as fundamental to the conceptualisation of QOL and the understanding of an individual’s wellbeing (Cummins, 2005). An individual’s expectation of their health and wellbeing can be greatly affected by a person’s perception of health and satisfaction with life. An assessment of QOL goes beyond symptomatology by considering the subjective impact of illness and life circumstances on an individual. This subjective evaluation is embedded in a cultural, social and environmental context, resulting in individuals and groups emphasising the importance of particular aspects of life (Orley & Kuyken, 1994). In a healthcare situation, a patient’s QOL is informed by an individual’s perspective of illness, perception of treatment, expectation of self, and appraisal of potential risk or harm that may arise (Roop, et al., 2012).

Lastly, the model illustrated in Figure 1 indicates the importance of personal values and aspirations in determining an individual’s QOL. This represents the relative weight or importance an individual attaches to various aspects of their objective life conditions and subjective wellbeing, and recognises individual differences in life goals and enjoyment derived from various activities (Felce, 1997). Individuals’ personal goals and aspirations may also differ across the lifespan, further adding to the conceptualisation of QOL as a fluid and subjective construct.

**Domains of quality of life.** Quality of life is almost always conceptualised as consisting of several dimensions, as shown in Figure 2. The most frequently cited are physical, psychological, and social wellbeing. A somatic/disease domain is included in some studies, in addition to a spirituality domain that refers to existential thoughts and seeking meaning through intra-, inter- and transpersonal connection (King, 2012;
Roop, et al., 2012). Other studies of QOL have also included material wellbeing (wealth, income, housing quality), productive wellbeing (competence, employment, hobbies), and civic wellbeing (privacy, public roles and responsibilities) (Felce, 1997). Each domain can be objectively assessed and subjectively perceived, and an global rating of QOL is often included to indicate a person’s overall wellbeing. Similarly to overall QOL, the facets of QOL domains are universal, but differ in their relative importance between and within individuals (Orley & Kuyken, 1994).

![Diagram of Quality of Life Domains](image)

*Figure 2. The global construct of quality of life and the quality of life domains of physical, psychological, and social functioning*

The structure and content of domains differ between studies and theories of QOL; however, most cover the same essential content despite variations in the overlap of variables between QOL (Fette, 2005). The physical domain of QOL comprises pain and discomfort, energy and fatigue, sexual activity, sleep and rest,
sensory functions, overall health, nutrition, mobility, and fitness. The psychological domain includes positive and negative feelings, self-esteem, body image and appearance, and the cognitive functions of thinking, learning, memory and concentration. Lastly, the social domain considers personal relationships, practical social support, role as provider or supporter, the quality and breadth of interpersonal relationships, intimacy, community involvement, social inclusions, and friends, relatives and acquaintances (Orley & Kuyken, 1994).

**Rationale, Aims, and Research Questions**

The literature previously reviewed suggests that organ transplantation is a well-researched area of study. Previous investigations have contributed to incredible advances in the medical aspects of organ transplantation, with today’s transplantation procedures affording excellent survival rates. Further research has investigated the psychiatric aspects of organ transplantation, medical compliance among transplant patients, and low posthumous donor rates.

The QOL of organ transplant patients has also been extensively studied, however, there has been no attempt to explain the QOL of transplant patients from a theoretical perspective, leading to much research simply re-establishing findings of differences in transplant patients’ QOL levels rather than seeking to identify the underlying factors associated with patients’ QOL (Dew, et al., 1997; Joralemon & Fujinaga, 1997). Furthermore, previous literature has been marred by a limited variety in research themes; most research has concentrated solely on QOL experiences from the perspective of transplant patients and has not considered the contribution or role of other people involved in the transplantation process, including health professionals and family members. As such, a comprehensive understanding of the many factors that contribute to the wellbeing of transplant patients has not yet been reached (R.
Taylor, Franck, Gibson, & Dhawan, 2005; Wood-Dauphinee, 1999). A more comprehensive understanding of the QOL issues of transplant patients from theoretical and empirical perspectives may also assist with improved intervention efforts, thereby assisting transplant patients to achieve optimal QOL.

In summary, the overall aim of the current thesis is to contribute to the understanding of the QOL of organ transplant patients by investigating new aspects of this widely researched topic. Thus far, a virtual plethora of research has failed to consider transplant patients’ QOL experiences from a theoretical perspective, and has largely failed to consider the perspectives of important others who play integral roles in the transplantation process. Adopting a theoretical perspective to investigate transplant patients’ QOL is incremental in filling a significant gap in this field of knowledge, and may also proffer an explanation of individual variability in the QOL reported by transplant patients. Further, consideration of QOL within the contexts of clinical practice and family life provides an opportunity to reach a more complete understanding of transplant patients’ QOL, thus enabling transplant patients to enjoy a life of optimal quality.

This thesis comprises three studies detailed in separate chapters. Each contributes unique knowledge to our understanding of the QOL experiences of organ transplant patients by focusing on QOL from the unique perspectives of transplant patients, medical professionals, and family members of pediatric transplant recipients. The aims and research questions pertaining to each study are herein detailed.

Study 1 adopted a theoretical stance, using the framework of crisis theory to consider the relative impact of stress and coping on the QOL outcomes for transplant patients. Consideration of the stress, coping, and QOL of transplant candidates and recipients was accompanied by comparisons with non-transplant individuals.
Transplant-specific stressors were also evaluated. The following research questions were posed:

1. Can the QOL of transplant patients be explained by crisis theory?
2. Do candidates, recipients and non-transplant individuals experience different levels of physical, psychological, and social functioning?
3. Do candidates, recipients, and non-transplant individuals experience different levels of everyday stress?
4. What are the coping strategies employed by candidates, recipients, and non-transplant individuals?
5. What are the prevalent transplant-specific stressors experienced by transplant patients?

Study 2 was an exploratory study that aimed to investigate QOL from the perspectives of health professionals working in the field of organ transplantation. With the aim of exploring health professionals’ attitudes towards QOL and their sensitivity towards the QOL issues of transplant patients, four research questions were posed:

1. How do health professionals define QOL?
2. What are the attitudes of health professionals towards transplant patients’ QOL issues?
3. Are health professionals willing to use QOL information in clinical practice?
4. To what extent do health professionals use QOL information in clinical practice, and what factors are associated with health professionals’ use of QOL information?
Study 3 investigated QOL from another perspective, with pediatric liver transplant patients’ QOL evaluated via parent proxy report. Additionally, pediatric transplant patients’ QOL was compared to a normative sample. This study also considered the way in which family routines are adjusted to accommodate for children following transplantation, and investigated the association between QOL and family functioning. Research questions for this study include:

1. Does the QOL of children who have received liver transplants differ from children in the community?

2. In which specific QOL areas do pediatric liver transplant recipients experience relative deficits?

3. Does the family functioning of pediatric liver transplant recipients differ from other children in the community?

4. Do family functioning and QOL improve with time-elapsed post-transplantation?

5. What is the relationship between family functioning and QOL of pediatric liver transplant recipients?
Chapter 2

Study 1 – Using Crisis Theory to Explain the Quality of Life of Organ Transplant Patients.

Study 1 investigates the QOL of adult transplant patients from a theoretical perspective, using crisis theory in an attempt to explain the ubiquitous QOL findings in the transplantation literature. Considerable previous research has reported that despite ongoing physical and psychological issues, transplant recipients report a much higher QOL than transplant candidates, and a comparable QOL to the healthy population (Burra & De Bona, 2007; Dew, et al., 1997; Edgar, 1996; Falger, Landolt, et al., 2008; Forsberg, Lorenzon, Nilsson, & Backmana, 1999; Kousoulas et al., 2008; Molzahn, 1991). However, these findings have not been explained from a theoretical perspective, leaving a considerable gap in the understanding of the QOL experiences of transplant candidates and recipients in comparison to others in the community. The introductory section of this chapter will follow the framework of crisis theory to detail the substantial previous research on transplant patients’ QOL, leading to a consideration of the relationship between stress, coping, and QOL.

Crisis Theory

Ecologists, sociologists and psychologists alike have long studied crisis, with diverse work from theorists such as Darwin and Freud concerned with the way humans react to unexpected and emergency situations and other predicaments (Moos & Schaefer, 1986). Derived from the Greek word krinein, meaning ‘to decide’, crisis is defined as a temporary state of upset and disorganisation, characterised by an inability to cope with a particular situation, and by the potential for a radically positive or negative outcome (Slaikeu, 1984). Examples of crises include threats to bodily integrity by illness, accident, or surgical operation (Moos & Schaefer, 1986);
organ transplantation, which typically involves waiting a substantial period of time for a suitable organ before undergoing transplant surgery, is a prime example of a life crisis. Caplan (1964) notes that crises are defined by being both serious and unavoidable situations that lead to a turning point in life development, likening a crisis experience to the storyline of a theatrical play, with life disrupted by some unexpected happening and a lead character portrayed as seeking a resolution yet struggling to find his way out of a quandary.

Crisis theory originated from Erich Lindemann’s (1944, cited in Caplan, 1964) seminal work on grief management, in which he theorised that teaching adequate mourning skills could prevent unhealthy coping among bereaved individuals. Caplan (1964) employed Lindemann’s broad conceptual framework to investigate life crises in adult psychopathology. Observing the history of psychiatric patients, he noted that those who coped with problems in an adaptive manner experienced better psychological outcomes.

Crisis theory is based on the assumption that individuals require a steady psychological equilibrium, similar to the need for physiological homeostasis. The theory contends that crisis disrupts psychological homeostasis, with an imbalance between problem severity and resources available to manage the situation often resulting in feelings of helplessness and ineffectuality. Similar to its physiological equivalent, psychological equilibrium must be restored relatively quickly in order to avoid distress or the developmental of psychopathology, and as such individuals experiencing a crisis must develop coping skills and resources outside their normal repertoire (Moos & Schaefer, 1986). The crisis may be a harmful experience, resulting in a reduced capacity to deal effectively with future crises, or a positive one, in which the individual applies newly-developed skills to other areas of life (Caplan,
1964). Returning to Caplan’s analogy of crisis as a theatrical production, equilibrium is signified by the central character settling down at the conclusion of the play, being portrayed as clearly better or worse off than at the play’s beginning.

In summary, crisis theory is concerned with how people cope with major life crises and transitions (Moos & Schaefer, 1986). Reflecting its beginnings, crisis theory continues to be applied to preventative psychiatry (Hobbs, 1984), and its framework has also been used to investigate coping in stressful employment settings (Sparks, 1988), parental stress and coping in pediatric critical care (LaMontagne, Johnson, & Hepworth, 1995), elderly persons’ transition to aged care facilities (Oleson & McGlynn Shadick, 1993), and the stress and coping of a pediatric burns patient and his caregivers (Fette, 2005). Crisis theory has also been used to explain cancer patients’ QOL, with the theory’s supposition supported by findings that patients undergoing treatment experience poorer QOL than patients in remission (Sprangers, Tempelaar, van den Heuvel, & de Haes, 2002).

**Understanding the crisis of physical illness.** Building on the initial crisis theory conceptualised by Caplan (1964), Moos and Schaefer (1986) developed an integrative framework in which serious physical illness is understood as a life crisis. Physical illness is a serious upset to a steady state that may extend over a long period of time and can potentially lead to permanent changes for patients. Ultimately, serious physical illness threatens life and wellbeing, and may involve additional stressors such as hospitalisation, medical procedures, reliance on medication, and extended separation from family and friends.

According to crisis theory, individuals experiencing physical illness use cognitive appraisal to assess the significance of the crisis, and then apply strategies to contend with its various stressors. As illustrated in Figure 3, crisis theory proposes
that an individual’s evaluation of these stressors and selection of effective coping strategies are influenced by demographic and personal characteristics, aspects of the illness, and the physical and social environment in which the illness occurs. These factors shape the individual’s appraisal of stressors and selection of coping mechanisms, leading to the crisis outcome (Moos & Schaefer, 1986). Echoing the sentiment of Caplan (1964), Moos and Schaefer (1986) noted that most people cope adequately with the crisis of severe physical illness, with many survivors reporting excellent post-crisis outcomes.

Figure 3. Crisis theory model. Adapted from Holahan, Moos, and Schaefer (1990)
Using crisis theory to understand the quality of life of transplant patients.

Moos and Schaefer’s (1986) crisis theory may be used to explore the QOL of transplant candidates and recipients. Crisis theory is particularly well suited to testing the QOL of transplant candidates; its supposition of the impact of crisis on QOL is congruent with the notion of end-stage organ failure and subsequent organ transplantation being an extreme health crisis, and the consideration of the contribution of stress and coping to the QOL of transplant patients is consistent with previous research in this field. The theory suggests that the QOL of transplant candidates (who are in crisis) will be impaired, as they possess insufficient coping skills to manage the crisis of being on the transplant waiting list. Candidates experience various stressors, including but not limited to the prospect of not receiving a transplant. The homeostatic equilibrium of a transplant candidate has been disrupted, and coping skills must be developed to restore psychological balance. Crisis theory suggests transplant recipients (post-crisis) have developed coping skills to overcome the crisis state and have adapted to their condition, resulting in overall QOL not being impaired despite probable physical and psychosocial restrictions (Holahan, Moos, & Schaefer, 1996).

Quality of Life After Organ Transplantation

Most studies report drastic improvements in QOL following organ transplantation. A comprehensive meta-analysis of 218 independent studies published between 1972 and 1996 reported transplant recipients generally experience improved QOL and show QOL advantages over transplant candidates (Dew, et al., 1997). Research has consistently found candidates’ QOL to be far worse in comparison to transplant recipients and the healthy population. Awaiting a transplant limits social and everyday activities, leading to a marked decline in QOL (Diaz-Dominguez,

Myaskovsky and colleagues (2003) found lung transplant candidates reported a lower QOL than two normative samples from the healthy population, with specific QOL deficiencies of lower general health, lower physical functioning, less vitality, more bodily pain, and greater difficulties with work, daily functioning, and social activities. Kalman, Wilson, and Kalman (1983) did not find a significant difference between the QOL of kidney recipients and dialysis patients, yet a comprehensive meta-analysis of published literature on the QOL of liver recipients found a significant improvement in overall QOL from pre- to post-transplant (Bravata, Olkin, Barnato, Keeffe, & Owens, 1999). While liver recipients report being satisfied with their lives (de Kroon, Drent, van den Berg, & Haagsma, 2007), findings of liver recipients’ QOL being comparable to that of the general population (Burra & De Bona, 2007; Dew, et al., 2007; Nickel, Wunsch, Egle, Lohse, & Otto, 2002) are tempered by longitudinal studies suggesting long-term deficits in liver recipients’ overall QOL (Kousoulas, et al., 2008; Lewis & Howdle, 2003).

More recent studies also note vast improvements between pre- and post-transplantation (Bortman et al., 1999; Diaz-Dominguez, et al., 2006; Kita & Tamaki, 1998; Limbos, Joyce, Chan, & Kesten, 2000; Moore, Mc, & Burrows, 2000; Rodrigue, Baz, Kanasky, & MacNaughton, 2005; Russ et al., 2007). However, the likelihood of observing post-transplant QOL benefits partially depends on the specific QOL domain and transplantation area under consideration. Beyond acknowledging such differences, previous research offers little consensus regarding QOL discrepancies between organ types, and a wide variety of research methodologies, tools and sample sizes make results difficult to reconcile. Limited investigation of candidates’ QOL has shown heart transplant candidates to have the worst QOL in
comparison to other groups (Pinson et al., 2000), however, heart recipients are
thought to have good long-term QOL prospects (Burra & De Bona, 2007). Previous
research on transplant recipients’ QOL has yielded varying results: Forsberg,
Lorenzon, Nilsson, and Backmana (1999) found no difference between the QOL of
lung, heart, and kidney recipients, but Diaz-Dominguez and colleagues (2006) noted
significant differences between kidney, lung, and heart groups. Further, a recent study
found no difference between the QOL of heart and liver recipients (Langenbach,
Schmeisser, Albus, & Decker, 2008), while lung recipients have been found to enjoy
a more optimal QOL than heart and liver recipients (Nickel, et al., 2002). Some
studies report renal patients to experience the best overall QOL improvements post-
transplant, with 23% of recipients reporting very good QOL, and 57% and 20%
reporting QOL as good or satisfactory, respectively (Burra & De Bona, 2007;
Lazzaretti, Carvalho, Mulinari, & Rasia, 2004; Wainwright, Fallon, & Gould, 1999).
In addition to an overall measurement, QOL can also be investigated in terms of
physical, psychological, and social wellbeing.

**Quality of life domains: Physical, psychological, and social wellbeing.** Meta-
analysis indicated important differences between the physical, psychological, and
social functioning of organ transplant patients (Dew, et al., 1997). Statistically
significant improvements were noted in the physical and social domains across all
organ types, but not in psychological wellbeing. Similarly, other studies have noted
deficits in recipients’ psychological wellbeing, with marked gains in physical and
social functioning but modest improvements in psychological health (Burra & De
Bona, 2007; Dew, Myaskovsky, et al., 2004). Conversely, a study comparing the
QOL of 371 liver, heart, kidney, and lung recipients identified significant physical
deficits but normal mental and emotional functioning (Pinson, et al., 2000). Heart
recipients studied 10-18 years after transplantation reported excellent overall QOL, but impaired physical health compared to the healthy population (Fusar-Poli et al., 2005). In contrast, an Italian study of 276 heart recipients surviving 10 years post-transplant found psychological wellbeing equal to the general population, while physical functioning was compromised (Politi et al., 2004). Denny and Kienhuis’ (2011) summary of the widely-investigated differences between the physical, social, and psychological functioning of heart, kidney, lung, and liver transplant patients further demonstrates the way in which transplant patients may experience differing QOL on each of the individual domains.

**Is recipients’ quality of life equal to the non-transplant population?** Crisis theory suggests transplant recipients will experience a superior QOL to candidates and a comparable QOL to the healthy population (Sprangers, et al., 2002). The former point has been demonstrated many times. The latter is partly dependent upon the type of organ transplanted, but literature suggests transplantation does not fully restore QOL to levels of the non-transplant population (Dew, et al., 1997). However, transplant recipients competing in the 1996 US Transplant Games reported an overall QOL higher than the general population, suggesting recipients have the potential to achieve excellent QOL (Painter et al., 1997). Several studies have explained similar findings with terminology consistent with crisis theory: recipients adjust to living with ongoing health problems, and begin to live a ‘new kind of normal’ life (Kugler et al., 2005; Moore, et al., 2000; Nickel, et al., 2002). While Kugler and colleagues (2005) reported recipients’ QOL to be comparable to the healthy population, a longitudinal study of 66 lung recipients found QOL did not reach normal levels of the US population (Rodrigue, et al., 2005). As QOL is a subjective experience (Murphy, Herrman, Hawthorne, Pinzone, & Evert, 2000), it may be that despite physical and
psychosocial problems, recipients perceive their lives as comparable to the healthy population (Dew, et al., 2007). After all, the alternative to organ transplantation is certain death.

**Stress**

Considerable research has attempted to link transplant patients’ QOL with coping strategies, yet few studies have systematically investigated the impact of stress on QOL outcomes. Only studies considering stressor characteristics can achieve a full understanding of the relationship between coping processes and illness outcome (S. Maes, Leventhal, & de Ridder, 1996).

**Stress and crisis theory.** Stress plays an important role in the conceptualisation of serious physical illness as a crisis. According to Moos and Schaefer (1986), an individual’s perception of stressors contributes to the selection of coping strategies. Seminal research on stress highlighted the important relationship between stress and coping mechanisms, noting that performance between individuals exposed to similar stressors was not uniformly impaired or facilitated (Lazarus & Folkman, 1984). Stress comprises physiological and psychological responses, and may be defined as the relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her wellbeing (Lazarus & Folkman, 1984). This definition acknowledges the subjective nature of stress, complementing the conceptual framework of crisis theory.

**Stress and organ transplantation.** Stress experienced by transplant patients has received little attention, but its importance should not be understated. Limited research suggests that the type and severity of patients’ stress influences the selection of coping styles and strategies, which ultimately impact upon QOL. Previous research has related transplant candidates’ increased stress to greater use of coping styles.
judged to be ineffective, such as confrontation, evasion, and self-reliance (Porter et al., 1994). Furthermore, high levels of stress have been found to interfere with medication adherence in kidney recipients, highlighting the importance of promoting optimal stress management in this population (Achille, et al., 2006).

Transplant candidacy is a stressful experience. Financial problems, social issues, weight loss, and ongoing medical treatment are likely to result in reduced QOL (Myaskovsky, et al., 2003). Previous research has identified that candidates worry most about deteriorating physical health, employment loss, reduced activity tolerance, relationship difficulties, medication side effects, and frequent hospitalisation (Moore, et al., 2000; Porter, et al., 1994). Additionally, candidates have valid concerns about their own mortality: the disparity between the supply and demand for transplantable organs means that it is likely that some transplant candidates will die before receiving a suitable organ (Excell, et al., 2011).

Transplantation does not eliminate stress. Recipients report ongoing concerns about organ rejection, financial worries, and adherence to rigid immunosuppressive regimens (Lindqvist, Carlsson, & Sjoden, 2004; Sutton & Murphy, 1989). Limited research has found liver recipients report higher stress levels than heart recipients (Langenbach, et al., 2008), while heart transplant recipients report similar amounts of stress compared to the healthy population (Grady, Jalowiec, & White-Williams, 1999).

**Coping**

Coping is an integral element of crisis theory, and the definition of coping as “a stabilising factor that can help individuals maintain psychosocial adaptation during stressful periods,” (Holahan, Moos, & Schaefer, 1996, p. 25) directly relates to the concept of psychological equilibrium. Most investigations of transplant patients’
Coping strategies employ Lazarus’ transactional approach, evaluating coping as responses to stress resulting from interactions with the environment (Lazarus & Folkman, 1984). Coping encompasses all cognitive and behavioural efforts to manage stress, and the development of coping skills is the focus of many psychotherapeutic and educational programs. Coping is subjective, and coping skills are contextual rather than a stable feature of personality: “… constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1986, p. 141).

Coping styles have been defined and categorised in many ways. Lazarus and Folkman (1986) distinguished between two general types of coping, with problem-focused coping aimed at taking action to alter the source of the stress, and emotion-focused coping aimed at reducing or managing emotional stress associated with a situation. While the broad distinction between problem- and emotion-focused coping is important, the initial dichotomy proved too simplistic, with further analysis revealing several activities pertinent to each (Carver, Scheier, & Weintraub, 1989). Based on the Lazarus model of stress, Carver and colleagues (1989) sampled undergraduate college students’ coping strategies, identifying five conceptually distinct aspects of problem-focused coping (active coping, planning, suppressing competing activities, restraint coping, seeking social support), five aspects of emotion-focused coping (seeking emotional support, positive reinterpretation, acceptance, denial, religion), and three aspects related to less useful coping strategies (venting of emotion, behavioural disengagement, mental disengagement). Carver’s conceptualisation of stress is widely used throughout the organ transplantation
Coping strategies of organ transplant patients. Studies investigating transplant patients’ coping strategies consistently report frequent use of problem-focused coping (Golfieri, et al., 2007; M. Maes, Sokal, & Otte, 1997; Myaskovsky, et al., 2003; Sutton & Murphy, 1989). Differing measures and categorisations of coping complicate comparisons, however, most can be identified as problem-focused or emotion-focused. Further, few studies consider the relationship between stress and coping with QOL, leaving no significant explanation of the major QOL differences observed between transplant patients and other members of the community.

Previous research has consistently found that transplant patients favour problem-based coping strategies. Myaskovsky and colleagues (2003) reported lung transplant candidates were likely to use problem-based coping strategies such as seeking support or taking action to deal with the problem, and Sutton and Murphy Pelletier (1989) found American renal patients often use prayer and problem-oriented skills such as looking at the problem objectively and seeking information. Intestinal transplant patients are also likely to seek support (Golfieri, et al., 2007). Transplant patients use emotion-focused coping less than the healthy population (Lindqvist, et al., 2004), with few patients using avoidance, humour, or excessive venting of emotions (Golfieri, et al., 2007; Myaskovsky, et al., 2003). However, transplant patients have been found to use acceptance, a form of emotion-based coping (Kaba, et al., 2000).

Many studies have made the general distinction between adaptive and maladaptive coping styles; however, it should be noted that a coping style itself is not effective or ineffective, and should be considered in relation to the stressor. Adaptive
coping styles, a subset of problem-focused coping characterised by planning, taking action and making the best of a situation, have been linked to physical and psychological wellbeing in medical patients (Stilley, Miller, Manzetti, Marino, & Keenan, 1999), but its relation to the QOL of transplant patients’ remains unclear. Scheier and Carver (1985) found that adaptive coping styles correlated with lower physical and psychological distress in heart transplant recipients, but further research found this coping style did not significantly predict QOL (Myaskovsky, et al., 2003). It is also important to consider the coping strategies not being employed by transplant patients, as decreased use of active coping skills has been related to low QOL (Stilley, et al., 1999; Telles-Correia, Barbosa, Mega, & Monteiro, 2009).

Additionally, the term maladaptive coping has been used to describe a variety of coping skills leading to undesirable QOL outcomes, and has been defined as not making use of medical, psychosocial, or personal resources (Nickel, et al., 2002). Avoidant coping, characterised by denial and attempts to shun stressful situations, is correlated with low QOL in HIV-positive individuals (Leiberich et al., 1997). Furthermore, in their comprehensive evaluation of psychiatric aspects of transplantation, Levenson and Olbrisch (1993) warn that candidates who avoid the reality of their situation do not cope effectively in cases of post-transplant complications or prolonged time on the waiting list.

Burker, Evon, Morroquin Loiselle, Finkel, and Mill (2005) investigated depression and disability as an outcome of heart candidates’ coping strategies, finding negative coping styles, such as behavioural disengagement and denial, significantly predicted depression. Further, mental disengagement and venting of emotions significantly predicted illness-related disability. Myaskovsky and colleagues (2003; 2005) found lung candidates’ avoidant coping significantly predicted overall poor
QOL. Specifically, avoidant coping, which is emotion-focused, significantly predicted physical (bodily pain) and psychological wellbeing (depression). These studies highlight an important fact: maladaptive coping skills, such as denial or disengagement, lead to poor QOL.

**Rationale, Aims, and Research Questions of the Current Study**

Exhaustive research has consistently reported significant overall improvements to QOL after organ transplantation. Studies generally report improvements in physical wellbeing and deficits in psychological functioning following transplantation. Limited research has established that transplant candidates and recipients encounter significant stressors, but a relative paucity of research has explored the relationship between the stress and coping of transplant patients. Literature has consistently shown frequent use of problem-focused coping skills among transplant patients, however, these have been considered as separate constructed in previous research, and as such there has been no attempt to investigate the implicit association between stress, coping skills and QOL.

The synthesis of information presented here allows the appraisal of well established findings in the literature, however, there remain significant gaps in our knowledge regarding the interaction between stress, coping styles, and QOL of organ transplant patients. Overall, previous research lacks a strong theoretical approach, and has failed to methodically consider the relationship between transplant patients’ stress, coping, and QOL. Crisis theory provides an ideal framework with which to explore this relationship, and has the potential to lead to a better understanding of the intricacies between transplant patients’ stress, coping, and QOL. This may assist in the design and implementation of psychosocial interventions aimed at improving patients’ coping skills and QOL by targeting specific stressors and coping styles.
The overall aims of Study 1 were to use crisis theory to explain organ transplant patients’ QOL and explore the differences in coping strategies, stress, and QOL between transplant candidates, transplant recipients, and the non-transplant population. A further aim was to explore the transplant-specific stressors experienced by transplant candidates and recipients. The following research questions were posed:

1. Can the QOL of transplant patients be explained by crisis theory?
2. Do candidates, recipients and non-transplant individuals experience different levels of physical, psychological, and social functioning?
3. Do candidates, recipients, and non-transplant individuals experience different levels of everyday stress?
4. What are the coping strategies employed by candidates, recipients, and non-transplant individuals?
5. What are the prevalent transplant-specific stressors experienced by transplant patients?

**Method**

**Participants**

The sample consisted of 226 participants representing three groups: (i) individuals currently on the waiting list for an organ transplant (‘transplant candidates’); (ii) individuals who have received an organ transplant (‘transplant recipients’); and (iii) individuals who have never been transplant candidates or recipients (‘non-transplant individuals’). Forty-five participants (19.8%) were transplant candidates, ninety-nine participants (43.6%) were transplant recipients, and eighty two (36.1%) participants comprised the non-transplant population. Full demographic details, including age, gender, annual income and country of origin of participants from each of the three groups is contained in Table 2. Most participants
were Australian and married, and had an average age 45 years. Information pertaining
to candidates’ and recipients’ specific organ types and time since transplant or time on
waiting list is also provided in Table 2. Most participants were awaiting or had
received a kidney transplant. The average time of candidacy was over two years,
while recipients were transplanted an average of six years prior to participating in the
study.

Table 2
Demographic Characteristics of Study 1 Participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Candidates $n = 45$ (19.8%)</th>
<th>Recipients $n = 99$ (43.6%)</th>
<th>Non-transplant $n = 82$ (36.1%)</th>
<th>Total $N = 226$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>20 (44.4%)</td>
<td>58 (59.2%)</td>
<td>28 (26.4%)</td>
<td>106 (46.7%)</td>
</tr>
<tr>
<td>Female</td>
<td>25 (55.6%)</td>
<td>40 (41.1%)</td>
<td>54 (45.4%)</td>
<td>120 (52.9%)</td>
</tr>
<tr>
<td>Mean age in years ($SD$)</td>
<td>52.52 (10.15)</td>
<td>53.91 (13.82)</td>
<td>31.92 (8.52)</td>
<td>45.60 (15.41)</td>
</tr>
<tr>
<td>Country of residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>37 (84.4%)</td>
<td>50 (57.1%)</td>
<td>58 (72%)</td>
<td>145 (67%)</td>
</tr>
<tr>
<td>United States</td>
<td>5 (11.4%)</td>
<td>27 (33.7%)</td>
<td>6 (12.2%)</td>
<td>38 (19.4%)</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>1 (2.3%)</td>
<td>4 (4.1%)</td>
<td>3 (3.7%)</td>
<td>8 (3.5%)</td>
</tr>
<tr>
<td>Canada</td>
<td>1 (2.3%)</td>
<td>2 (2%)</td>
<td>10 (12.2%)</td>
<td>13 (5.7%)</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>3 (5%)</td>
<td>2 (4%)</td>
<td>5 (2.2%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>26 (59.1%)</td>
<td>69 (69.7%)</td>
<td>19 (24.7%)</td>
<td>114 (50.7%)</td>
</tr>
<tr>
<td>In a relationship</td>
<td>5 (9.1%)</td>
<td>5 (5.1%)</td>
<td>30 (38.3%)</td>
<td>40 (17.6%)</td>
</tr>
<tr>
<td>Single</td>
<td>8 (18.2%)</td>
<td>12 (12.1%)</td>
<td>25 (30.9%)</td>
<td>45 (19.8)</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>6 (11.4%)</td>
<td>9 (9.1%)</td>
<td>4 (6.2%)</td>
<td>19 (8.4%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>1 (2.3%)</td>
<td>4 (4%)</td>
<td>-</td>
<td>5 (2.2%)</td>
</tr>
<tr>
<td>Organ type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart</td>
<td>1 (3%)</td>
<td>32 (32.3%)</td>
<td>-</td>
<td>33 (22.3%)</td>
</tr>
<tr>
<td>Lung(s)</td>
<td>2 (4.7%)</td>
<td>21 (21.2%)</td>
<td>-</td>
<td>23 (16.2%)</td>
</tr>
<tr>
<td>Kidney</td>
<td>32 (74.4%)</td>
<td>19 (19.2%)</td>
<td>-</td>
<td>51 (38.5%)</td>
</tr>
<tr>
<td>Spleen</td>
<td>-</td>
<td>1 (1%)</td>
<td>-</td>
<td>1 (0.8%)</td>
</tr>
<tr>
<td>Liver</td>
<td>2 (4.7%)</td>
<td>15 (15.2%)</td>
<td>-</td>
<td>17 (10.8%)</td>
</tr>
<tr>
<td>Heart and lung</td>
<td>-</td>
<td>3 (3%)</td>
<td>-</td>
<td>3 (1.5%)</td>
</tr>
<tr>
<td>Heart and pancreas</td>
<td>-</td>
<td>1 (1%)</td>
<td>-</td>
<td>1 (0.8%)</td>
</tr>
<tr>
<td>Pancreas and kidney</td>
<td>6 (14%)</td>
<td>5 (5.1%)</td>
<td>-</td>
<td>11 (7.7%)</td>
</tr>
<tr>
<td>Lung and kidney</td>
<td>-</td>
<td>2 (2%)</td>
<td>-</td>
<td>2 (1.5%)</td>
</tr>
<tr>
<td>Mean time in months on waitlist ($SD$)</td>
<td>25.42 (22.49)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mean time in months since transplant ($SD$)</td>
<td>-</td>
<td>73.92 (63.68)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Materials

Participants completed a questionnaire comprising measures related to stress, coping, and QOL. Two versions of the questionnaire were available: the first was completed by non-transplant participants, and included measures of perceived stress, coping, and QOL (see Appendix A); the second was completed by participants from the transplant group (candidates and recipients), and included an additional measure related to stressors experienced by transplant patients and the perceived strain of the transplant experience (see Appendix B). The questionnaires were available online and in hardcopy format.

Demographic information was collected from all participants. Additionally, transplant candidates were asked to indicate the length of time spent on the transplant waiting list and organ type required, and transplant recipients were asked to indicate time elapsed since the transplant procedure and organ type received.

General stress. The Perceived Stress Scale (S. Cohen, Kamarck, & Mermelstein, 1983) is a 14-item scale used to assess general perceived stress related to day-to-day life, that is, stress not necessarily related to the transplant process. Respondents were asked to indicate the degree to which they have experienced symptoms of stress over the past month (0 = never, 4 = very often). With a possible overall score ranging from zero to fifty-six, higher scores denote higher levels of perceived stress. The reliability rating for the original measure and the current study was Cronbach’s $\alpha = .86$ and $\alpha = .77$, respectively (S. Cohen, et al., 1983).

Coping. The 28-item Brief Coping Orientation to Problems Experienced Scale (Carver, 1997) was used to evaluate participants’ coping styles. The Brief COPE is derived from the original COPE inventory (Carver, et al., 1989), and assesses fourteen coping strategies such as active coping, denial, positive reframing, humour, and self-
blame. Respondents were asked to indicate on a four-point scale (1 = I don’t do this at all, 4 = I do this a lot) how often they use particular way of coping. For example, “I get emotional support from others” is an item indicative of active coping. The fourteen coping strategies are grouped into three coping categories by summing relevant items, with higher scores indicating greater preference for the use of the coping strategy. The three coping strategies and associated subscales (with items and Cronbach’s α from the original scale and current study, respectively) were problem-focused coping (active coping, planning, instrumental support, and religion; α = .80, α = .76), active emotional coping (venting, positive reframing, humour, acceptance, and emotional support; α = .81, α = .74), and avoidant coping (self-distraction, denial, behavioural disengagement, self-blame, and substance use; α = .88, α = .70).

**Quality of life.** The WHO Quality of Life Scale – BREF (Murphy, et al., 2000) was used to gather information about participants’ perception of their global QOL, and QOL in the domains of physical, psychological, and social functioning. The WHO-QoL BREF also includes a subscale of environmental QOL; this was not calculated in the current study as to maintain consistency with previous transplantation studies. Participants were asked to consider their standards, hopes, pleasures and concerns in relation to their life within the last two weeks, with all items rated on a 5-point scale (1 = very poor, 5 = very good). A profile of domain scores and an individually scored global QOL was produced for each participant. To allow for comparisons across domains, items pertaining to physical, psychological, and social functioning are summated and transformed to a 0-100 scale. The original scale demonstrated high levels of internal consistency on the measures of overall QOL, and the QOL domains of physical (α = .87), psychological (α = .81), and social functioning (α = .68) (Murphy, et al., 2000). The current study also showed high
levels of reliability: global QOL ($\alpha = .75$), and the domains of physical ($\alpha = .83$), psychological ($\alpha = .82$), and social functioning ($\alpha = .75$).

**Transplant-specific stress.** Transplant candidates and recipients also completed an additional measure to quantify the type and severity of transplant-related stress. The Transplant Patients’ Perceived Stress Scale (TPPSS) was adapted for use in the current study from the Transplant-Related Stressors Scale (TRSS) (Frazier, et al., 1995). The TRSS was originally designed to measure stress in kidney transplant recipients. Respondents rated sixteen items on a five-point scale, with higher scores from a total possible score of 80 indicating higher levels of transplant-related stress. The scale also comprises five sub-scales of potentially stressful events, including future health issues (fear of organ rejection, susceptibility to other illnesses, uncertainty about future health), finances (handling insurance, financial pressure), medication side effects and physical limitations (dietary restrictions, medication side effects, weight gain, appearance change, energy levels), interpersonal relationships (lack of social support, relationship with significant others, being a burden), and following a medical regimen and dealing with the medical community (following doctors’ orders, having medical questions answered, travelling to appointments). Subscale scores were obtained by summing relevant items and averaging by the number of items in each subscale. The overall reliability of the original scale was Cronbach’s $\alpha = .89$, and with the exception of financial stress subscale ($\alpha = .56$) all stressor subscales of the original scale showed acceptable internal consistency, ranging from $\alpha = .70$ to $\alpha = .84$. In the current study, the overall reliability was $\alpha = .87$, with all measures except the financial subscale ($\alpha = .32$) demonstrating acceptable levels of internal consistency. The modest internal consistency of this TPPSS subscale may be a reflection of its low number of items.
Procedure

Participants completed the questionnaire in paper-and-pencil format or online using SurveyMonkey software. Fifty three (23.35%) participants completed hardcopy questionnaires returned via reply-paid postage, while one hundred and seventy four (75.65%) completed the questionnaire online. All participants completed a demographic section, followed by measures related to stress, coping, and QOL. Transplant candidates and recipients also completed the measure of transplant-related stress, the TPPSS.

Participants were recruited from a variety of sources; non-transplant participants were recruited via a convenience sample (online and public advertisements), and transplant patients were recruited from online and community support groups frequented by transplant patients. Additionally, the Monash Medical Centre’s (MMC) Department of Nephrology assisted with recruitment by distributing information and questionnaire packs to approximately 100 patients currently waiting for a transplant. Approval from the Southern Health Research Directorate Ethics Committee was obtained prior to recruitment. An MMC employee was responsible for distribution of questionnaire packs to patients, thus ensuring confidentiality and anonymity.

An information sheet (see Appendices C and D) accompanying both forms of the questionnaire advised participants of the general purpose of the study and the requirement that participants be aged 18 years or over. Patients from MMC received a plain language statement that adhered to the regulations of the Southern Health Research Directorate Ethics Committee (Appendix E). All participants were also advised of the voluntary nature of the study and their right to withdraw from the study anytime prior to submitting the completed questionnaire. Consent to participate in the study was implied through return of the questionnaire. The questionnaire included no
identifiable information, and anonymity and confidentiality was further assured by reply-paid postage or online questionnaire submission.

Results

Preliminary Data Analysis

The questionnaire data were analysed using Statistical Package for the Social Sciences (SPSS) version 18.0. Due to a large amount of missing data pertaining to the transplant-specific stress scale, data relating to this scale was removed from the dataset in order to limit the effect of missing data on the overall dataset and to allow for separate analysis of transplant-specific stressors.

Fifteen cases were removed from the sample prior to data analysis being performed, as they were missing more than 30% of data on at least one scale. The fifteen cases represented two participants from the non-transplant population and thirteen transplant recipients. The total sample for analysis, therefore, comprised 212 participants, including 45 transplant candidates (21.2%), 87 transplant recipients (41%), and 80 non-transplant participants (37.7%).

Remaining cases were analysed for the presence of missing data. Analysis showed data to be missing at random, and as such missing values were replaced with the sample mean for that variable, thus ensuring a complete dataset. The data were then examined to ensure assumptions regarding normality, outliers, linearity, homogeneity of variance, and multicollinearity were met. Examination of histograms and z scores revealed divergence from normality for the variables of stress, global QOL and the three QOL subsets, and problem-focused coping and avoidant coping. The QOL variables were not transformed, as previous research suggests global QOL and its domains to be generally rated positively. Transformation on the remaining variables did not improve skewness. Further, the sample size was large (\(N = 212\), and
the primary methods of data analysis employed in the present study are relatively robust to normality violations when a large sample is used (Tabachnick & Fidell, 2007). Inspection of the P-P Normality plot suggested no major deviations from normality. Several multivariate outliers were identified (Mahalanobis’ Distance values at $p < .001$), but as the original and trimmed means were very similar for all variables, the outlying cases were retained in the dataset (Tabachnick & Fidell, 2007). Collinearity statistics showed no multicollinearity or singularity.

**Descriptive Statistics**

Descriptive statistics for the present sample are also presented in Table 3. Overall, participants reported a high global QOL, together with comparably high self-reports in the QOL domains of physical, psychological and social functioning. Participants reported experiencing low to moderate levels of everyday stress. Most participants reported predominantly using an active-emotional coping style, with fewer employing avoidant coping strategies.
Table 3  
*Descriptive Characteristics of Study 1 Variables*

<table>
<thead>
<tr>
<th>Measure/Variable</th>
<th>Candidates $n = 45$</th>
<th>Recipients $n = 87$</th>
<th>Non-transplant $n = 80$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$ &amp; $SD$</td>
<td>$M$ &amp; $SD$</td>
<td>$M$ &amp; $SD$</td>
</tr>
<tr>
<td>PSS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>25.80 .93</td>
<td>22.67 7.61</td>
<td>25.29 5.77</td>
</tr>
<tr>
<td>Brief-COPE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem-focused</td>
<td>2.46 .57</td>
<td>2.67 .66</td>
<td>2.57 .51</td>
</tr>
<tr>
<td>Active-emotional</td>
<td>2.66 .49</td>
<td>2.70 .47</td>
<td>2.71 .55</td>
</tr>
<tr>
<td>Avoidant</td>
<td>1.82 .49</td>
<td>1.68 .41</td>
<td>1.85 .17</td>
</tr>
<tr>
<td>WHO-QoL BREF</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global QOL</td>
<td>71.11 20.70</td>
<td>84.14 15.90</td>
<td>85.25 17.36</td>
</tr>
<tr>
<td>Physical QOL</td>
<td>61.46 16.94</td>
<td>71.92 15.83</td>
<td>80.11 13.37</td>
</tr>
<tr>
<td>Psychological QOL</td>
<td>70.58 15.91</td>
<td>77.47 16.73</td>
<td>72.70 15.11</td>
</tr>
<tr>
<td>Social QOL</td>
<td>65.04 19.34</td>
<td>70.96 20.18</td>
<td>72.75 18.32</td>
</tr>
<tr>
<td>TPPSS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall transplant</td>
<td>42.58 12.93</td>
<td>35.01 10.29</td>
<td>- -</td>
</tr>
<tr>
<td>-related stress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Future-health</td>
<td>2.90 1.05</td>
<td>2.19 .83</td>
<td>- -</td>
</tr>
<tr>
<td>Finances</td>
<td>2.60 1.04</td>
<td>2.31 .95</td>
<td>- -</td>
</tr>
<tr>
<td>Medication side-effects and physical limitations</td>
<td>2.76 .96</td>
<td>2.37 .70</td>
<td>- -</td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td>2.78 1.00</td>
<td>2.25 .91</td>
<td>- -</td>
</tr>
<tr>
<td>Medical regimen and medical community</td>
<td>2.28 .91</td>
<td>1.92 .73</td>
<td>- -</td>
</tr>
</tbody>
</table>

*Note. PSS – Perceived Stress Scale; Brief COPE; WHOQoL BREF – World Health Organisation Quality of Life Scale BREF; TPPSS – Transplant Patients’ Perceived Stress Scale.*

**Testing Crisis Theory**

A one-way between-groups ANOVA was conducted to explore the impact of transplant status on Global QOL, as measured by the WHO-QoL BREF. Participants were divided into three groups according to their transplant status: transplant candidate, transplant recipient, or non-transplant individual. As the assumption of homogeneity of variance was violated (Levene’s $p = .043$), the Brown-Forsythe result was interpreted, $F = 9.75 (2, 137) = 9.75, p = .000, \eta^2 = .01$. While a statistically significant difference was detected, the effect size was small, showing a modest actual difference between the groups. Post-hoc comparisons using the Tukey
HSD test indicated that the mean Global QOL score for transplant candidates was lower and statistically different \((p = <.001)\) from transplant recipients and non-transplant respondents. There was no significant difference \((p = .91)\) detected between transplant recipients’ and non-transplant respondents’ Global QOL ratings.

To test crisis theory (see Figure 3, p. 33), a standard multiple regression was performed to determine the relative contribution of stress and coping to the overall QOL of transplant patients. The groups of candidates and recipients were collapsed in order to form the group of transplant patients, due to the relatively small number of candidates participating in the study. Firstly, the relationships between QOL and the variables of transplant-related stress (future health, finances, medicine side-effects and physical limitations, interpersonal relationships, medical regimen and medical community), stress, and coping (problem-focused, active-emotional, avoidant coping) were investigated using Pearson product-moment correlation coefficients (see Table 4). No significant relationships were detected between QOL and any of the transplant-related stress variables. Significant relationships were identified between avoidant coping and QOL \((r = -.358, n = 132, p <.001)\), and everyday stress and QOL \((r = -.522, n = 132, p <.001)\). This indicates that less use of an avoidant coping style was associated with higher QOL, and that lower levels of stress were also associated with higher QOL.

Based on the crisis theory’s supposition of the roles of coping and stress in relation to QOL, the variables of avoidant coping and general stress that were found to be significantly associated with transplant patients’ QOL were entered into the regression to test the predictive abilities of the theory (Moos & Schaefer, 1986). Results, presented in Table 5, show that the two variables significantly predicted QOL, \(R^2 = .23, F (2, 131) = 25.07, p = .000\). Together, the two variables accounted for
22.5% of variance in the model. Only the variable of everyday stress was found to contribute significantly to the prediction of transplant patients’ QOL. Avoidant coping was not shown to have a significant effect on QOL.

Quality of Life Domains

A one-way between-groups multivariate analysis of variance (MANOVA) was performed to investigate the differences in the QOL domains of physical, psychological, and social functioning between the three groups of transplant candidates, transplant recipients, and non-transplant individuals. There was a statistically significant difference between the three groups on the combined QOL domains: \( F(3, 207) = 12.31, p = .00; \) Wilks’ Lambda = .72, \( \eta^2 = .15. \) When the results for the QOL domains were considered separately, the only difference to reach statistical significance, using the Bonferroni adjusted alpha level of .01, was physical functioning, \( F(2, 209) = 21.92, p = .006, \eta^2 = .013. \) Follow-up comparisons using Tukey HSD showed the mean scores for physical functioning were statistically significantly different between all groups: candidates and recipients \( (p = .001), \) candidates and non-transplant individuals \( (p = .000), \) and recipients and non-transplant individuals \( (p = .002). \) These differences are depicted in Figure 4, which shows the levels of physical, psychological, and social functioning of the three groups.
Table 4

*Intercorrelations Between Transplant Patients’ Global Quality of Life, Coping, Transplant-Related Stress, and Everyday Stress (N = 132)*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
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<th>4</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Global QOL</td>
<td></td>
<td>1</td>
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<td></td>
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<tr>
<td>2. Problem-focused coping</td>
<td>.16</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>3. Active-emotional coping</td>
<td>.15</td>
<td>.57**</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
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<tr>
<td>4. Avoidant coping</td>
<td>-.36**</td>
<td>.17*</td>
<td>.26*</td>
<td></td>
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<td></td>
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<td></td>
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<tr>
<td>5. Transplant stress - future health</td>
<td>-.06</td>
<td>.054</td>
<td>.06</td>
<td>.02</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. Transplant stress - finances</td>
<td>.05</td>
<td>.13</td>
<td>-.04</td>
<td>.01</td>
<td>.46**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Transplant stress - physical</td>
<td>-.07</td>
<td>.08</td>
<td>.11</td>
<td>.05</td>
<td>.60**</td>
<td>.38**</td>
<td></td>
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<tr>
<td>8. Transplant stress - interpersonal</td>
<td>.07</td>
<td>.12</td>
<td>.09</td>
<td>-.09</td>
<td>.46**</td>
<td>.45**</td>
<td>.65**</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>9. Transplant stress - med regimen</td>
<td>.04</td>
<td>.03</td>
<td>.13</td>
<td>.05</td>
<td>.45**</td>
<td>.37**</td>
<td>.60**</td>
<td>.49**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Everyday stress</td>
<td>-.52**</td>
<td>.06</td>
<td>-.04</td>
<td>.64**</td>
<td>.03**</td>
<td>.13</td>
<td>-.01</td>
<td>-.06</td>
<td>-.06</td>
<td></td>
</tr>
</tbody>
</table>

*Note:* *p < .01, **p < .05.*
Table 5
Summary of Standard Multiple Regression Analysis of Organ Transplant Patients’
Quality of Life (N = 132)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant coping</td>
<td>3.23</td>
<td>3.16</td>
<td>.08</td>
<td>[-3.01, 9.47]</td>
</tr>
<tr>
<td>Everyday stress</td>
<td>-1.25</td>
<td>.19</td>
<td>-.52*</td>
<td>[-1.64, -.87]</td>
</tr>
</tbody>
</table>

Note. $R^2 = .23$, *$p < .001$, CI = confidence interval

Figure 4. Physical, psychological, and social functioning of candidates, recipients, and non-transplant individuals.

**General Stress**

Inspection of the mean scores of everyday stress experienced by transplant candidates, as measured by the PSS, showed that candidates experience the most stress related to everyday activities, followed by non-transplant individuals. Transplant recipients report experiencing the least everyday stress. A summary of the mean PSS scores for each group can be found in Table 3.
A one-way between groups ANOVA was conducted to explore the differences between the everyday stress experienced by transplant candidates, transplant recipients, and non-transplant individuals. Normality assumptions were met, however, as the assumption of homogeneity of variance was violated (Levene’s $p < .05$), Brown-Forsyth results were interpreted. Using the Bonferroni adjusted alpha level of .01, differences in perceived stress between the groups did not reach statistical significance, $F(2, 166) = 4.44, p = .013, \eta^2 = .04$. However, results showed a trend towards differences between recipients experiencing different levels of stress than candidates ($p = .035$) and non-transplant individuals ($p = .037$).

**Coping Styles**

The mean scores of coping styles, summarised in Table 2, showed that all groups reported most frequently using active-emotional coping, followed by problem-focused coping and avoidant coping. Transplant candidates were least likely to use problem-focused coping in comparison to transplant recipients and non-transplant individuals. Similarly, transplant candidates reported being least likely to use active-emotional coping in comparison to transplant recipients and non-transplant individuals. Avoidant coping was most employed by non-transplant individuals and transplant candidates, while transplant recipients were least likely to use avoidant coping.

One-way between-groups MANOVA was performed to investigate differences in coping styles between transplant candidates, transplant recipients, and non-transplant individuals. Three coping styles were investigated: problem-focused, active-emotional, and avoidant coping. Using the conservative alpha level of .01 due to the violation of the assumption of homogeneity of variance, no statistically
significant differences were found between the groups’ coping styles, $F(6, 414) = 2.07, p = .056$; Wilks’ Lambda = .94, $\eta^2 = .03$.

**Transplant-Specific Stress**

One hundred and seventeen transplant patients completed the TPPSS measure of transplant-specific stress, including 65 males (56%) and 51 females (44%). Eighty six (73.5%) were transplant recipients, with most having received a heart (27), lung (18), kidney (18), or liver (13). Thirty one (26.5%) were transplant candidates, with most awaiting a kidney (20).

An independent samples t-test was conducted to compare the transplant-related stress of transplant candidates and recipients. Results indicated transplant candidates experience greater transplant-specific stress compared to transplant recipients, $t(115) = 3.27, p = .001$, $\eta^2 = .08$. Figure 5 shows candidates’ and recipients’ comparative experiences of transplant specific stressors, and descriptive statistics are detailed in Table 2. Transplant candidates’ most prevalent concern was future health, followed by interpersonal relationships, finances, medication side effects and physical limitations, and medication regimen and dealing with the medical community. Transplant recipients ranked medication side effects and physical limitations as the most prevalent concern, followed by finances, interpersonal relationships, future health, and medical regimen and medical community. The comparative variability in scores across the groups, as shown in Figure 5, indicates a greater variation in stress experienced by transplant candidates and implies less predictability in their experience of transplant-specific stress.
Discussion

Much previous research has investigated the QOL of transplant patients, and the differences between candidates’ and recipients’ QOL has been repeatedly noted in the literature. However, by considering the intricate relationship between stress, coping, and transplant patients’ QOL through the framework of crisis theory (Moos & Schaefer, 1986), the current study is the first to offer a theoretical perspective on this heavily researched topic. Comparisons between transplant recipients, transplant candidates, and non-transplant individuals were made with respect to general and domain-specific QOL, in addition to an exploration of the transplant-specific concerns of transplant patients. Each research question will now be considered in turn, leading
to generalised conclusions. Limitations of the current study and suggestions for future research will also be discussed.

**Using Crisis Theory to Explain Organ Transplant Patients’ Quality of Life**

Findings of the current study show that crisis theory provides a valid explanation of the QOL of transplant patients. Applying crisis theory to this population validates the theory, and provides an explanation for the QOL of organ transplant patients. Crisis theory postulates that people in crisis will experience lower QOL in comparison to people who are no longer in crisis and those who have not experienced a crisis. In keeping with this hypothesis, the results of the current study showed transplant candidates reported the lowest levels of overall QOL. Additionally, post-crisis transplant recipients reported a similar overall QOL to non-transplant individuals. Further, the results indicate the change in QOL across the transplant experience: QOL is compromised prior to transplantation, with transplantation enabling a restoration of QOL to levels comparable with the general population. This provides support for the notion of resiliency gained through experience; transplant recipients generally consider their QOL to be reasonably high despite living with likely ongoing health difficulties and managing ongoing medical appointments and a regimen of medication.

These findings support much previous research, and endorse the results of an earlier meta-analysis which espoused great QOL improvements from pre- to post-transplantation across all organ-types (Dew, et al., 1997). The findings of transplant recipients reporting much better overall QOL in comparison to transplant candidates is also congruent with more recent findings regarding QOL improvements among lung, liver, kidney, and heart recipients (Bravata, et al., 1999; Limbos, et al., 2000;
Further supporting the framework of crisis theory, the current study revealed comparable QOL ratings of transplant recipients and non-transplant individuals. This finding lends credence to crisis theory’s hypothesis that post-crisis individuals experience QOL akin to that of individuals who have not experienced a crisis. Several studies investigating the QOL of transplant patients have also reported the QOL of transplant recipients to be comparable to non-transplant individuals (Burra & De Bona, 2007; Dew, et al., 2007; Nickel, et al., 2002). However, these findings are contrary to previous research that concluded long-term deficits in the QOL of kidney (Kalman, et al., 1983) and liver recipients (Kousoulas, et al., 2008; Lewis & Howdle, 2003).

The current findings add to a convincing body of research that has demonstrated the QOL benefits of transplantation. Despite lifestyle restrictions and uncertainty regarding organ rejection and illness relapse, it appears that recipients are able to quickly adapt to post-transplantation life. Similarly to the experience of transplant patients in the current study, much literature has focused on the positive benefits and post-traumatic growth experienced by individuals following adverse events such as cancer, strokes, natural disasters, criminal victimisation, grief, and combat (McMillen, 1999). Several explanations posited for experiencing benefit from adversity may also be applied to the QOL experiences of transplant patients. Recollections of a life-threatening illness are not likely to be easily forgotten, giving recipients a context in which post-transplantation life may be considered ideal, despite ongoing health difficulties. Views on the importance of valuing self and others may be changed following a serious health crisis such as end-stage organ failure and transplantation.
Further, transplant recipients may be responding to pre-transplant expectations held by themselves and others by exceeding their previous QOL. Recipients’ goals for life may be altered following a life-threatening illness, leading to increased participation and enjoyment of activities not previously undertaken. Research has also pointed to the experiences of people realising a spiritual awakening or increased religiosity following serious health crises, with changes to life structure and personal values associated with improved physical and mental health (McMillen, 1999). Such conjecture echoes Caplan (1964): struggling with a crisis may lead to increased coping skills, enhanced self-efficacy, and improved ability to cope with future adverse events.

**Contribution of coping and stress to transplant patients’ quality of life.** The current study demonstrates the usefulness of explaining QOL from a theoretical perspective, with crisis theory’s supposition partly supported by findings that stress contributes significantly to transplant patients’ QOL. The experience of stress was identified as an important determinant of transplant patients’ QOL. These findings add to considerable previous literature concerning the relationship between transplant patients’ coping strategies and QOL.

Avoidant coping was not found to make a significant contribution to the QOL of organ transplant patients. Specifically, while an association was detected between an avoidant coping styles and lower levels of overall QOL, results of the standard multiple regression revealed that avoidant coping does not significantly predict transplant patients’ QOL. Current results partly support previous findings of avoidant coping being associated with poor QOL in transplant patients (Levenson & Olbrisch, 1993), however, contradict previous findings of lung candidates’ avoidant coping predicting overall poor QOL (Myaskovsky, et al., 2003). While not found to
significantly predict QOL, the finding of an association between avoidant coping and QOL implores researchers and health care professionals to heed Stilley and colleagues’ (1999) advice to pay special attention to the wellbeing of all transplant patients, as not seeking help or declining assistance may be evidence of avoidant coping.

Transplant-specific stress was not found to be associated with transplant patients’ QOL. However, the present study demonstrated the significant impact of experiences of general stress, such as handling personal problems and feeling overwhelmed by demands, on transplant patients’ QOL. Little prior research has investigated transplant patients’ experiences of general stress; it may be that the focus on keeping transplant patients alive during candidacy overshadows consideration of the impact of stressful daily experiences impact upon wellbeing.

Several practical implications for assisting transplant patients arise from this finding. Transplant patients may require support with daily activities, as it appears they are susceptible to becoming overwhelmed by life’s irritations and hassles. Patients may benefit from learning stress-reduction techniques, such as relaxation strategies, anger management or problem-solving strategies. Previously found to be important to medication adherence (Achille, et al., 2006), the relevance of promoting stress management among patients is now further substantiated by current findings of the adverse impact of stress on transplant patients’ QOL.

Physical, Psychological, and Social Functioning

In addressing the second research question, non-statistically significant differences were observed across candidates, recipients and non-transplant populations with regard to QOL in the domains of physical, psychological, and social functioning. Statistically significant differences were observed only in the domain of
physical functioning. The current findings corroborate previous assertions of improvements in QOL being dependent on the specific domain under consideration (Dew, et al., 1997).

Overall, the trend of results in the current study indicated transplant candidates to have the lowest levels of functioning in each of the QOL domains, however, differences between the groups did not reach statistical significance. Non-transplant individuals experienced the best physical and social functioning, however, transplant recipients reported the highest level of psychological functioning. These findings are contrary to those shown in meta-analysis, which noted significant improvements in physical and social domains across all organ types, but not psychological QOL (Dew, et al., 1997). A possible explanation for these inconsistent findings may be differing levels of community psychological awareness and greater access to psychological care at the time of the current study in comparison to the studies comprising the meta-analysis. Improved life expectancy following transplantation due to advances in immunosuppressive medicines may also lead to lower levels of psychological distress. Recipients’ worries about organ rejection and the need for retransplantation may be partly alleviated by increased donor rates and reduced waiting times (Excell, et al., 2011), with previous research linking increased time spent waiting for an organ with higher levels of anxiety and depression (Vermeulen, Bosma, Bij, Koeter, & Tenvergert, 2005).

**Physical functioning.** Given the compromised physical health and dire medical condition of people awaiting a transplant, it was expected that transplant candidates’ QOL related to physical functioning would be rated lower than that of transplant recipients and non-transplant individuals. Symptoms of end-stage organ failure include fatigue, insomnia, pain, nausea, weight loss, and immobility. Palliative care is
often necessary for patients who do not receive a transplant in adequate time (Janssen, et al., 2008).

Current results indicate that transplantation improves physical QOL, but does not restore it to the pre-illness levels. This finding is congruent with previous research that identified vast differences in physical QOL between heart candidates and recipients (Fusar-Poli, et al., 2005), and also upholds meta-analysis findings (Dew, et al., 1997).

**Psychological functioning.** The psychological functioning of transplant recipients in the current study was found to be high, with self-ratings of psychological QOL higher than those of transplant candidates and non-transplant individuals. However, the differences in the current study were not found to be statistically significant, with the trend of results contributing to mixed findings in the literature; Burra and De Bona (2007) stated that recipients gained only modest improvements in psychological health while others noted good mental and emotional wellbeing and psychological functioning equal to the general population (Pinson, et al., 2000; Politi, et al., 2004).

Psychological functioning encompasses emotional, cognitive and behavioural status, taking into account overall distress, depressive and anxiety symptoms, and self-image. Transplant candidates’ psychological difficulties may be explained by the emotional turmoil and uncertainty of waiting for an organ transplant. The trend of low psychological QOL reported by transplant candidates in the current study is consistent with the finding of a high prevalence of depression, anxiety, alcohol or substance abuse or dependence, and adjustment disorders among transplant candidates (Telles-Correia, et al., 2009).
It is intriguing that the trend of results showed that transplant recipients reported experiencing better psychological functioning than non-transplant individuals. While this difference did not reach statistical significant, this may be explained in a similar manner to which post-crisis experiences of overall QOL are conceptualised; resiliency following an adverse life event such as organ transplantation appears to enhance psychological coping skills and enable better psychological functioning. Alternatively, the cross-sectional design of the present study may be reflecting the long-term psychological wellbeing of patients who underwent organ transplantation a considerable time ago, as the average time since transplant among recipients in the current study was six years. Previous research has indicated that onset of psychiatric conditions such as major depressive disorder, posttraumatic stress disorder (PTSD) and adjustment disorder is rare beyond the first twelve months following transplantation (Dew et al., 2005).

The findings related to the psychological QOL of transplant patients suggests adequate psychological assistance is afforded to transplant recipients, however, there appears to be an increased need for assessment and treatment of psychological illness among transplant candidates. Further, serious pre-transplant psychological disorders have been shown to indicate risk for post-transplant psychological distress (Dew, et al., 2005), and is a good indicator of medication adherence (Fredericks, Lopez, Magee, Shieck, & Opipari-Arrigan, 2007). Potential transplant candidates undergo psychological evaluation to identify probable risk factors to postoperative compliance and recovery, such as substance use, serious psychopathology, and cognitive impairment. While a great deal of variation exists in the format of psychological screening between transplant centres, there is general consensus of the importance of this procedure to ensure scarce donor organs are used wisely with respect to morbidity
and mortality outcomes (Olbrisch, et al., 2002). Similarly, there is acknowledgment of the need for immediate post-transplant support for transplant recipients with reference to medication adherence, employment rehabilitation, and possible organ rejection. However, ongoing psychological assessment and support of transplant candidates is not normally provided beyond initial preoperative screening (Zipfel, et al., 1998). Formal assistance for family members is limited and many transplant teams do not employ a psychologist or psychiatrist, despite the finding that up to 47% of transplant candidates express a need for counselling (Goetzmann et al., 2006). Previous research and findings of the present study indicate a clear need for the investigation and implementation of intensified psychological treatment for organ transplant candidates.

**Social functioning.** Statistically significant differences were not observed between the social functioning of candidates, recipients, and non-transplant individuals. Based on an individual’s perception of their role and relationship with others, social functioning reflects social interactions, leisure, intimate relationships, and experiences with friends and family. Low ratings of social functioning among transplant candidates in the current study may be explained by lifestyle restrictions experienced by people waiting for an organ transplant, with patients typically unable to work or participate in usual leisure activities such as sport. Medical appointments and frequent hospitalisation disrupt the independence of daily living activities, and transplant candidates must remain nearby the transplant centre or hospital, as organs must be transplanted within a relatively short amount of time (Engle, 2001). The low social functioning among candidates in the present study is congruent with established findings of substantial changes in relationships between transplant patients and their spouses and family members following high levels of stress and adjustment (Frazier, et al., 1995).
Given the lifestyle restrictions faced by transplant candidates, the findings of no significant differences in their social functioning in comparison to recipients and non-transplant individuals was surprising; perhaps this indicates the low value candidates place on social functioning during a time when physical health and waiting for a transplantation dominates life. While the current findings suggest transplantation does not fully restore social functioning to the level of non-transplant individuals, the trend of results appear to suggest that transplantation grants recipients freedom to pursue social interaction, partake in relationships, and fulfil role based goals such as employment and leisure activities.

**General Stress**

Findings of the current study substantiate the important role of general stress in relation to the capacity of crisis theory to explain the QOL of organ transplant patients. While no significant differences were detected between the levels of general stress experienced by transplant candidates, recipients, and non-transplant individuals, it is noteworthy that transplant candidates reported lowest levels of everyday stress. In keeping with Caplan’s (1964) explanation of resiliency following crisis, it may be speculated that the stressful experience of organ transplantation equips recipients with adaptive coping strategies that are maintained following transplantation. Further, the everyday hassles leading to general stress may be perceived as less burdensome for recipients who have endured the trauma of end-stage organ failure and the transplantation process.

**Coping Styles**

The important relationship between coping style and QOL has been evidenced in the current study and prior research (Burker, et al., 2005; Myaskovsky, et al., 2003). Current findings are consistent with previous research that found few
transplant patients employ avoidant coping, such as behavioural disengagement and mental disconnection (Golfieri, et al., 2007; Myaskovsky, et al., 2003).

While postulations regarding coping styles are tempered by no findings of statistical difference between the group’s coping styles in the current study, it is noteworthy that there was a trend towards recipients reporting the lowest levels of avoidant coping. This lends a modicum of credence to crisis theory’s hypothesis of increased adaptive coping skills following the experience of a crisis, and supports the notion of coping being a contextual rather than stable feature of personality (Lazarus & Folkman, 1984). This flexibility provides an ideal opportunity for health professionals to intervene in the early stages of the transplantation process in order to enhance patients’ adaptive coping skills. With the present study supporting previous research pointing to an association between coping style and QOL of transplant patients, future research should concentrate on interventions to increase patients’ use of adaptive coping skills. Preliminary research has indicated that participation in cost-effective web-based and telephone-based interventions is associated with increased use of adaptive coping skills among transplant patients (Dew, Goycoolea, et al., 2004; Napolitano et al., 2002). While limited, such research points to the need for further investigation and development of interventions aimed at encouraging transplant patients to develop adaptive coping skills.

Transplant-Specific Stress

Although experiences of transplant-specific stress were not found to be predictive of transplant patients’ QOL, important differences were noted between the types and amount of transplant-specific stress experienced by candidates and recipients. Overall, transplant candidates reported significantly higher levels of transplant-specific stress. Furthermore, recipients’ reports of ongoing stress appear to
support the notion of stress not being completely eliminated by transplantation (Lindqvist, et al., 2004; Sutton & Murphy, 1989).

The transplant-specific concerns of candidates and recipients also differed. Candidates worried most about future health, interpersonal relationships, and finances, and were least worried by medication side effects and physical limitations, and medication regimens and dealings with the medical community. However, recipients were most worried about medication side effects and physical limitations, finances, and interpersonal relationships, worrying least about future health and medication regimen and dealings with the medical community. These findings endorse previous research that found candidates worried most about deteriorating physical health, relationship difficulties, employment, and medication side effects (Moore, et al., 2000; Porter, et al., 1994). Not surprisingly, candidates worried most about future health, including receiving an organ transplant in a timely manner. Further, candidates’ worries regarding interpersonal relationships are congruent with compromised social functioning.

Interestingly, candidates and recipients were both least concerned with medication regimens and dealings with the medical community. This is contrary to previous studies that reported transplant patients’ concerns with adhering to medication regimens (Lindqvist, et al., 2004; Sutton & Murphy, 1989). While lifelong medication continues to be necessary for all transplant patients, this discrepancy may be explained by recent advances in immunosuppressive medication that has led to reductions in long-term medication dosages. Finances remain a pertinent concern during candidacy and following transplantation. This is an unsurprising finding with regards to transplant candidates, given the impact of end-stage organ failure on patients’ ability to work. Recipients’ concerns regarding finances may indicate the
long-term effect of the transplantation process on employment and the ability to generate an income, and may also reflect the long-term costs of transplantation including medical appointments and medication expenses.

**Limitations of the Current Study and Directions for Future Research**

The present study has added new knowledge to a considerable body of literature by investigating QOL from a theoretical perspective. However, several limitations should be noted when considering the generalisability of the current findings. First, while some studies point to differences in the QOL of transplant patients related to type of organ, differences between candidates and recipients of specific organ types was not considered in the current study due to variation in numbers of participants related to each specific organ. Additionally, demographic factors such as gender and income were not considered. Second, the cross sectional nature of the study meant that differences related to time on waiting list to receive a transplant or time elapsed were not controlled for. A longitudinal design would be ideal to investigate the intricate differences in QOL between pre- and post-transplantation, however, time constraints and the unpredictable nature of candidates’ time spent on waiting list make such studies difficult in the field of transplantation research. While the inclusion of the non-transplant comparison group is a particular strength of the current study, these individuals may indeed have experienced another type of serious medical illness or other life crisis not controlled for in the current study. Such crises may have impacted upon their responses, thus effecting results of the current study. Third, a large number of participants did not complete the transplant specific stress questionnaire; this may be due to difficulty understanding the questions or a belief on the behalf on transplant recipients that the questions were applicable only to transplant candidates. Last, the current study tested crisis theory related to all
transplant patients, as the relatively small number of transplant candidates recruited to the study meant that separate multiple regressions could not be conducted on the individual groups of transplant candidates and recipients. Further to this, there were different levels of QOL across the groups. Ideally, a larger sample size would have allowed separate regressions for both groups, which may possibly identify differences in the way in which stress and coping predict QOL in transplant candidates and recipients.

Although the current study is the first to consider transplant patients’ QOL from a theoretical perspective, there remain many possibilities for innovative research within this field. Similar to most previous research, the current study has investigated the general experiences of transplant patients as a group. However, as experiences vary between individuals more specific investigations should be conducted. Qualitative research that details individual experiences of the transplantation process may enable a richer understanding of patients’ QOL. Further, with the QOL benefits of transplantation well established by decades of research, one of the next logical research steps may be to investigate effective interventions to optimise QOL among candidates and recipients. With preliminary research heralding the promising outcomes of internet and telephone based interventions, other interventions may include evaluation of existing support groups for candidates and recipients, and appraisal of bibliotherapy in the form of self-help books and brochures. Such interventions should aim to decrease patients’ use of avoidant coping by engaging individuals. Given current findings regarding the impact of general stress on QOL, interventions should also aim to assist transplant patients to overcome difficulties with everyday tasks. Lastly, future research aiming to explore transplant patients’ QOL from a theoretical perspective may include a measure of self-esteem, as previous
research has implicated the role of self-esteem in patients’ ability to maintain optimal QOL during and after a crisis (Sprangers, et al., 2002).

Concluding Comments and Practical Implications

The current study has explored several concepts related to transplant patients’ QOL that have previously been researched as separate constructs. The relationship between stress, coping, and QOL was explored using the framework of crisis theory, showing that the QOL of transplant patients can be explained from a theoretical perspective. The findings of the current study supported crisis theory’s supposition of enhanced coping strategies following a crisis, and results were congruent with the hypothesis that people experiencing a crisis have compromised QOL in comparison to people who have endured a crisis and those who have not experienced crisis. Results highlighted the important interplay between coping, stress, and QOL, with the revelation of a relationship between avoidant coping, perceived stress, and lower QOL. These findings offer clear directions for future research and interventions to assist transplant patients achieve optimal QOL during candidacy and post-transplantation.

Overall, the current study has clearly demonstrated the QOL benefits of transplantation. With the medical intervention of transplantation producing excellent survival rates, the next challenge for transplant personnel is to apply new knowledge regarding the complex relationship between stress and coping to ensure every transplant patient experiences optimal QOL and can make the most of their second chance at life.
Chapter 3

Study 2 – Health Professionals’ Attitudes Toward Transplant Patients’ Quality of Life Issues

Our understanding of the QOL experiences of transplant patients has been enriched by decades of research, with investigations such as Study 1 of this thesis proving the QOL benefits of the life-saving procedure of transplantation. However, the emphasis of much previous research on the QOL of transplant candidates and recipients belies an important fact: transplantation is a process rather than an event. Many people, including a large number of health professionals, accompany patients throughout the transplantation process and may potentially impact upon the QOL of transplant patients, yet literature in this field is primarily focused on patients’ perspectives and largely fails to reflect health professionals’ views of QOL issues.

The current study investigates health professionals’ perceptions of QOL and willingness to consider transplant patients’ QOL issues. Additionally, perceived barriers to health professionals’ use of QOL information in clinical practice with transplant patients are evaluated, leading to a consideration of the incongruence between attitudes, willingness, and behaviour with regard to clinical use of QOL information.

Health Professionals Involved in Organ Transplantation

Receiving a suitable organ and undergoing transplant surgery is the pinnacle event of the transplantation process, yet the time preceding and following surgery comprises the enduring experience of organ transplantation. This lengthy process involves the provision of care and support from an indefinite number of health professionals with a variety of expertise and experience. The type, intensity, and longevity of contact between health professionals and patients and their families
contribute to the unique nature of the relationship between healthcare providers and organ transplant patients.

Known collectively as a ‘transplant team’, the group responsible for the care of transplant patients is an interacting network of health professionals who work collaboratively with patients for the sole purpose of optimising transplant care and education. Transplant teams are an essential part of the transplantation process, and can be credited with contributing to the improved lives of patients with end-stage organ failure through lowering mortality and morbidity rates and improving psychosocial experiences for patients and families (Back, 2000; Paris et al., 1995).

The main charge of the transplant team is the careful selection and management of patients likely to survive and thrive with transplant surgery. The exact composition and nature of each transplant team varies within and between institutions and is dependent upon local demands and the availability of resources, however, it is usually a multidisciplinary team including specialists from surgery, internal medicine, nursing, psychology or psychiatry, and social work. Each member of the team holds specific duties and responsibilities according to their individual training and expertise. Back (2000) provides an interesting commentary on the challenges and rewards of working on a multidisciplinary transplant team. Professionals from other fields such as anesthesia, occupational or physical therapy, and nutrition, are often also involved in the care of transplant patients (Olbrisch, et al., 2002). Hospital chaplains also play an integral role in many organ procurement cases (Carey, Robinson, & Cohen, 2009). Donor and transplant coordinators manage the activities of the transplant team by identifying potential donor recipients, overseeing the donor consent process, arranging surgical retrieval of donor organs, providing for the safe transport of
organs, organising ongoing care for families, supporting the team of health professionals, and maintaining records (Paris, et al., 1995).

Regardless of differences within and between transplant teams, all Australian health professionals working with transplant patients are ethically bound to ensure a complete separation of the roles between those involved with care of the deceased donor and their family and those involved with the care of recipients. A governance position is assigned to one professional within the team to ensure all procedures are duly followed, with thorough records of process kept to maintain confidentiality and privacy of both donors and recipients (Rudge, Matesanz, Delmonico, & Chapman, 2012).

**Quality of Life and Clinical Practice**

Despite general recognition of the essential role of healthcare professionals in the transplantation process, there has been little formal consideration of the way in which health professionals working within the transplantation field view QOL issues, nor has there been any investigation of the extent to which clinical practice is sensitive to transplant patients’ QOL needs. Previous research of health professionals working within the field of transplantation has not considered QOL issues, instead focusing on the training needs of transplant surgeons (Reich et al., 2011) and medical matters such as surgical techniques and survival rates (Cotler, et al., 2003; Levine, 2004; Schiano, et al., 2001).

Studies of QOL within oncology and general medicine have brought attention to the importance of considering the way in which QOL information is used within clinical practice. Health professionals frequently make judgments about QOL when making decisions about patient care, and their perceptions of patients’ QOL may be a key factor in determining whether effective treatment for life threatening conditions
should be given or withdrawn (Addington-Hall & Kalra, 2001). While the patient represents the most appropriate source of knowledge regarding their own QOL, some patients may be unwilling or unable to provide QOL information due to cognitive impairments, communication deficits, or severe distress (Wilson, Dowling, Abdolell, & Tannock, 2000). Indeed, it is precisely for these patients that QOL information is most needed to inform appropriate decision-making. From a theoretical perspective, QOL is defined from the patient’s view, however, it is essential to investigate QOL from all aspects, as health professionals’ interpretation of QOL status is frequently used as a proxy and is therefore integral to the care and treatment of organ transplant patients.

As agents of change, health professionals have the potential to help patients achieve optimal QOL. Detmar, Aaronson, Wever, Muller, and Schornagel (2000) found that higher patient satisfaction and better health outcomes among oncology patients were related to health professionals enquiring about emotional concerns in addition to physical health concerns, with patients expressing a desire for their doctors to understand the impact of disease on their daily functioning and QOL. Routine consideration of QOL also allows for the monitoring of changes in wellbeing over time, and encourages patients and health professionals to work collaboratively on prioritising problems, facilitating communication, and identifying treatment preferences (Janse et al., 2004). King, Ferrell, Grant, and Sakurai (1995) contend that health professionals must seek to understand patients’ perceptions of illness in order to avoid over-emphasis on technical and medical oriented treatment. Consideration of QOL issues encourages holistic care that assists patients to achieve psychological wellbeing and social functioning in addition to physical wellness.
Understanding patients’ QOL has important implications for treatment and therapy options. However, Farquhar (1995) points to a lack of agreement among clinical, research, and patient perspectives of QOL, noting that consensus on a definition and an agreed upon understanding of the term is rare. Further, several studies have identified discrepancies between patients’ and health professionals’ observations of QOL. Meta-analysis revealed that patients’ and doctors’ perceptions of QOL are not normally matched (Janse, et al., 2004), and a study of European nephrologists treating renal transplant patients found that doctors generally underestimated the extent of patients’ QOL difficulties (Ekberg et al., 2007). Further, doctors and patients have been found to disagree on symptom severity, a factor that may influence QOL; a study within a palliative care setting showed increased disagreement on symptomatology between doctors and patients as symptom severity increased, with doctors showing a consistent bias towards underestimating illness severity (Stephens, Hopwood, Girling, & Machin, 1997). Despite this finding, previous research has indicated that doctors usually achieve greater accuracy in identifying objective domains such as physical QOL in comparison to subjective domains such as psychological wellbeing (Janse, et al., 2004). Conversely, Wilson and colleagues (2000) found good general agreement between one-hundred oncology patients and their physicians regarding QOL, however, cautioned that several cases of substantial discordance in doctor and patient QOL ratings were observed. Studies investigating nurses’ observations of the QOL of end-stage renal disease patients and bone marrow transplant recipients indicate that nurses generally perceive patients to have lower QOL in comparison to patients’ subjective ratings (King, et al., 1995; Molzahn, 1991; Molzahn, et al., 1997).
The way in which health professionals interpret and apply QOL information is important to the treatment and care of organ transplant patients. With previous research indicating that health professionals rely on potentially inaccurate QOL judgments when making decisions about the wellbeing and management of patients, the use of QOL information within transplantation medicine warrants investigation.

**Understanding Attitudes to QOL Issues and Willingness to Use QOL in Clinical Practice**

Thus far, ample coverage of QOL within the organ transplantation literature has excluded any investigation of health professionals’ attitudes to QOL issues or willingness to consider QOL information in clinical practice. Health professionals’ consideration of QOL within clinical practice has received a comparatively greater amount of attention within the oncology literature, with previous research indicating the importance of ascertaining health professionals’ perspectives on QOL and demonstrating the way in which such information can be used improve the QOL experiences of patients (Bezjak, et al., 2001).

Health professionals’ understanding of the term QOL has implications for the measurement and assessment of QOL and may also impact upon interpretation and understanding of QOL information. However, it is currently unclear whether health professionals share a unanimous understanding of the term that is widely acknowledged as a nebulous concept and has been defined in a variety of ways (Cummins, 2005; Orley & Kuyken, 1994). Farquhar (1995) argues that the diversity of individuals’ definitions of QOL is influenced by cultural factors, age, professional and personal experiences, leading to likely divergence among health professionals’ understanding and use of the term.
Investigations of health professionals’ understanding of QOL have been extremely limited, and the way in which organ transplant health professionals define the term has not yet been evaluated. While 88% of oncologists reported being able to define QOL, the remainder reported it to be a fluid, changing, abstract concept that could not be measured (K. M. Taylor, MacDonald, Bezjak, Ng, & DePetrillo, 1996). Oncologists defined QOL in relation to patients’ sense of wellbeing, performance status, and illness status. Conversely, McKeveitt, Redfern, La-Placa, and Wolfe (2003) reported that only 2% of health professionals (doctors, physiotherapists, occupational therapists) working with stroke patients described QOL as indefinable. Most respondents defined QOL as patients’ happiness, related to enjoyment of life, having life choices, personal dignity, and lack of worry in life. Considerably fewer considered the social, physical, and psychological domains of QOL, and only 13% of respondents commented on the subjective nature of QOL.

Attitudes towards QOL issues and willingness to use QOL information have also received scant attention. Attitude towards QOL is defined as health professionals’ thoughts about the concept of QOL, opinion of QOL instruments, and perception of benefits and disadvantages of using QOL in clinical practice. Willingness refers to health professionals’ reported intention to use QOL information in clinical practice (Bezjak, et al., 2001). Studies consistently report that health professionals hold a positive attitude towards QOL and view QOL issues as highly important: 97% of general practitioners (GPs) report QOL to be fairly important or very important (Skevington, Day, Chisholm, & Trueman, 2005), while the vast majority of oncologists also viewed QOL considerations as important (K. M. Taylor, et al., 1996). Further, Lee and colleagues (2004) found that most doctors reported feeling very comfortable discussing QOL issues with patients, with 73% reporting
regular discussions regarding QOL issues with patients when making treatment decisions. These results appear to reflect relatively frequent consideration of QOL issues among health professionals, however, little is known about the way in which QOL issues are linked to clinical decision-making, nor are clear details provided regarding the nature, frequency, or extent of QOL discussions between doctors and patients.

**Health Professionals’ Use of QOL Information in Clinical Practice**

While QOL issues appear to be held in high regard by health professionals, there is an apparent incongruence between the positive attitude towards QOL issues and the use of QOL information in clinical practice. Results of an Australian study exemplify this disparity: 80% of oncologists reported that QOL data should be collected prior to the commencement of treatment, yet only 50% reported actually doing so (Morris, Perez, & McNoe, 1998). A study of the QOL attitudes of physicians working in the field of hematopoietic stem cell transplantation also reflected disparity between intent and behaviour regarding QOL information; most purported QOL consideration to be important yet only 28% of physicians reported using QOL information to inform treatment decisions (Lee, et al., 2004).

Previous research has also shown that health professionals typically apply QOL assessment in a variety of ways, with many reaching QOL decisions through informal assessment. In keeping with their medical training, doctors generally assess QOL during unstructured clinical interviews. Doctors tend to imply QOL through evaluation of observable aspects such as physical functioning, absence of symptoms, laboratory test results, and social indicators of wellbeing such as returning to work (Frost, Bonomi, Ferrans, Wong, & Hays, 2002; Skevington, et al., 2005). The use of such traditional medical markers to imply QOL complicates the evaluation of health
professionals’ use of QOL, as informal assessment limits the ability to accurately report and analyse information pertaining to the use of QOL information in clinical practice.

**Use of QOL measures in clinical practice.** Quality of life measures have long been used in research with organ transplant patients (Dew, et al., 1997; Molzahn, 1991), yet little is known about the use of such measures within clinical practice. The use of QOL measures in clinical practice has been strongly advocated in previous research, as results provide a quantification of change over time, and can be used as a foundation for QOL discussions with patients (Frost, et al., 2002). Further, while research has indicated health professionals’ preference for informal assessment of QOL through clinical interview, such assessments may be adversely impacted by health professionals’ inaccurate judgments or subjective feelings of optimism or negativity (Addington-Hall & Kalra, 2001). Stephens and colleagues (1997) are adamant about the need to employ formal QOL measures in clinical practice, stating that only the enforced use of questionnaires can reconcile levels of agreement on QOL ratings between doctors and patients, leading to optimal treatment decisions and best patient outcomes. However, it appears such measures are not highly utilised by health professionals: oncologists report infrequently using formal measures (Frost, et al., 2002), and 52% of British GPs surveyed by Skevington and colleagues (2005) reported no knowledge of QOL scales.

The feasibility and usefulness of administering QOL questionnaires in routine clinical practice with transplant patients has been investigated in two previous studies. Santana and colleagues (2010) conducted a randomised control trial (RCT) investigating the inclusion of a QOL measure in the clinical care of lung transplant patients. Findings revealed that patients who completed QOL measures discussed
more QOL issues with doctors, and rated the quality of communication with their
doctor higher than other patients. However, no association was found between routine
completion of QOL measures and improved QOL. Similarly, an earlier study assessed
the use of QOL measures within routine clinical practice with renal patients
undergoing dialysis treatment, in which nurses administered and reviewed a
specialised measure of renal patients’ QOL (Wild, Grove, Keogh, & Farina, 2000).
Responses from 46% of patients were flagged as requiring follow-up for issues
including depression, fatigue, and mobility problems. Of patients contacted by nurses
to discuss QOL issues, 70% agreed to onward referrals to other professionals. The
study concluded that measurement of QOL is practical and worthwhile in routine
clinical nursing practice with transplant patients.

A number of QOL measures are available for use in clinical practice, including
several generic QOL measures that are suitable for use with organ transplant patients.
While the majority of oncologists report being concerned with the validity and
reliability of such scales (K. M. Taylor, et al., 1996), most measures have excellent
psychometric properties. The Quality of Life Uniscale (Spitzer et al., 1981) is an
efficient assessment that allows patients to rank areas of life according to lowest and
highest quality. The SF-36 (McHorney, Ware, & Raczek, 1993) assesses physical,
social, emotional and functional wellbeing, and while commonly used in research it
may also be used with individual patients. The Patient-Generated Index (Ruta,
Garratt, Leng, Russell, & MacDonald, 1994) allows patients to list up to five areas of
life significantly affected by their medical condition, with ratings then assigned to
each according to the extent of difficulties experienced. Transition scales and time
trade-off scales (Joyce, O'Boyle, & McGee, 1999) offer a novel approach to assessing
QOL; patients provide direct judgments about QOL improvement or deterioration, and are able to express preference for QOL over longevity of survival.

A small number of transplant-specific measures of QOL that allow for assessment of clinically relevant factors are also available. Transplant-specific measures are designed to identify patients at different levels of morbidity, determine the differential impact of treatment options, identify patients at risk of emotional difficulties and regimen adherence, and posit potential long-term difficulties (Weissberg-Benchell et al., 2010). The PedsQL™ Transplant Module (Weissberg-Benchell, et al., 2010) was designed in response to the lack of pediatric QOL measures, and is a well-validated and highly reliable measure of pediatric transplant patients’ QOL. Specific measures have also been developed for gastrointestinal transplant patients (Borgaonkar & Irvine, 2000). The End-Stage Renal Disease-Symptom Checklist and the Kidney Disease Quality of Life Questionnaire are useful in the assessment of renal patients’ QOL (Butt, Yount, Caicedo, Abecassis, & Cella, 2008). With a broad range of measures available, clinicians and researchers should carefully select measures to reflect their intended use and allow for comparisons with other transplant patients and non-transplant individuals.

**Dissemination of transplant research to clinical practice.** The substantial increase in the publication of QOL studies within the transplantation literature over the past few decades is indicative of the considerable research attention that has been afforded to the QOL of transplant patients. Improvements in the QOL of transplant patients may be implicitly attributed to the propagation and application of QOL research findings. However, there has been no formal study of the dissemination of research to clinical practice, and as such the usefulness of continued research in this area has not yet been ascertained.
Findings that 65% of hematopoietic stem cell transplant doctors do not read studies reporting QOL results (Lee, et al., 2004) are indicative of concerns regarding the divide between QOL research and clinical practice. Guyatt and Schunemann (2007) suggest that clinicians often do not read published studies due to difficulty of interpreting findings. As such, researchers have been urged to present QOL findings in simple, accessible terms that delineate a level of QOL requiring intervention (Koller, Klinkhammer-Schalke, & Lorenz, 2005). However, the suggestion of dividing QOL scores into dichotomous categories of ‘good’ and ‘bad’ contradicts the conceptualisation and definition of QOL as a subjective construct that is shaped within a cultural and personal context. Till, Osaba, Pater, and Young (1994) summarised the issues related to lack of dissemination of health-related QOL research into practical applications, noting an imbalance between the interests and priorities of researchers and clinicians, and encouraging increased multidisciplinary collaboration to ensure mutual interest and practicality in research topics. Lenfant (2003) also observed problems with the dissemination of research to clinical practice, urging researchers and clinicians to come together to ‘close the loop’ between theory and practice by applying established research findings in clinical practice. This transition would also enable QOL research to expand its focus to other areas related to transplantation, such as the design and evaluation of interventions focused on increasing health professionals’ use of QOL information in clinical practice.

The utility of ongoing research in the field of organ transplantation heavily depends on the applicability and usefulness of research findings to clinical practice. Conceptual debates and replication of established findings are futile unless these can be applied to efforts to understand and improve transplant patients’ QOL. As such, an investigation of the way in which QOL research is disseminated among
transplantation health professionals is needed to clarify the current standing of research and inform the future direction of study.

**Perceived Barriers to the Collection and Use of QOL Information**

Health professionals frequently cite time constraints and workload burdens as the main barriers to collecting and using QOL information. Concerns about time required for longer consultations to discuss QOL issues have been reported, together with extra time required to administer and score QOL measures (Skevington, et al., 2005). Morris and colleagues (1998) found that oncologists’ perceptions of lack of appropriate instruments impacted upon assessment of QOL, together with the belief that QOL evaluation is unnecessary and should remain the domain of other health professionals, such as psychologists. The perceived added burden to workload also encompasses the need to acquire knowledge and skills about QOL assessment, together with the obligation to follow-up patients’ QOL concerns with an intervention or referral to another health professional. Similarly, Unruh, Wesibord, and Kimmel (2005) state that health professionals face multiple challenges in assessing and applying QOL information, including understanding the conceptual model of QOL, assessing the quality of literature, and the logistic difficulties associated with incorporating QOL data into the routine of busy clinical practice.

While health professionals’ main concerns with incorporating QOL assessment into clinical practice are associated with additional time and workload burdens, research has shown routine assessment of QOL does not require prolonged patient consultations (Santana, et al., 2010). The inclusion of routine QOL assessment may actually lower health professionals’ time and work commitments, as it has been found to be associated with more efficient and effective medication changes and increased rate of referral to other specialists.
Rationale, Aims, and Research Questions of the Current Study

As detailed in this chapter, there has been a scarcity of research investigating QOL issues from the perspective of health professionals working within the field of transplantation. Discord between patients’ and health professionals’ QOL ratings revealed in previous research indicates a pressing need to investigate the way in which QOL is perceived and used within clinical practice with transplant patients. Further, there has been no assessment of the dissemination or application of copious amounts of published research related to the QOL of transplant patients, leading to the replication of studies and little knowledge of the utility of accrued research.

The overall aim of the current study was to extend knowledge of transplant patients’ QOL experiences by considering QOL from the perspective of health professionals working within transplantation medicine. It is anticipated that this exploratory investigation will provide an indication of the way in which QOL is considered in transplantation clinical practice, and will inform strategies to ensure transplant patients’ QOL remains a treatment priority. Four research questions were posed in this exploratory study:

1. How do health professionals define QOL?
2. What are the attitudes of health professionals towards transplant patients’ QOL issues?
3. Are health professionals willing to use QOL information in clinical practice?
4. To what extent do health professionals use QOL information in clinical practice, and what factors are associated with health professionals’ use of QOL information?
Method

Participants

The sample consisted of 41 health professionals working in the field of transplantation. All participants were working in Australia at the time of the study. Nine were doctors, twenty-six nurses, four allied health professionals including physiotherapists and dietitians, and two did not state profession. The majority of participants (78%) were female. Twenty-seven (65.9%) worked in pediatrics, 11 (26.8%) with adults, and 3 (7.3%) in combined pediatric/adult settings. Most worked primarily in patient care (58.5%) while others were employed in roles that combined patient care, administration, and teaching. Thirteen health professionals (31.7%) worked specifically with liver transplant patients, and four each (9.8%) with cardiac, renal, and lung patients, respectively. Remaining participants worked across a range of combined organ types. With an average age of 40.54 years ($SD = 10.19$), most health professionals completed training between 1991 and 2000 (34.1%) or after 2000 (31.7%), while others trained between 1980 and 1990 (24.4%) or prior to 1980 (9.8%).

Materials

Participants completed a questionnaire designed to evaluate attitudes, willingness, and behaviour towards the QOL issues of organ transplant patients (see Appendix F). Additionally, participants were asked to provide a definition of QOL. Demographic information related to age, gender, profession, area of expertise, clinical population, and practice responsibilities was also collected.

MD-QOL. The MD-QOL (Bezjak, et al., 2001) was used to measure attitudes to QOL, willingness to use findings of QOL, and behaviour related to QOL in clinical practice. The MD-QOL is a 47-item measure designed to quantify health
professionals’ attitudes to QOL in the three main areas of attitude, willingness, and behaviour related to the use of QOL information in clinical practice. Attitude towards QOL was defined as measuring health professionals’ thoughts about the concept of QOL, opinion of QOL instruments, and perceptions of the benefits and drawbacks of using QOL in clinical practice. Willingness was conceptualised as the intention to use QOL information, while behaviour incorporated the extent to which health professionals used formal and informal QOL information in clinical decision-making. Several items were negatively worded and subsequently reverse scored, with all items measured on a 4-point Likert scale from strongly disagree to strongly agree. The MD-QOL has shown good psychometric properties, with internal consistency reliabilities of Cronbach’s $\alpha = .80$, $\alpha = .75$, and $\alpha = .81$ for the subscales of attitude, behaviour, and willingness to use QOL, respectively. The current study demonstrated comparable reliabilities of Cronbach’s $\alpha = .66$, $\alpha = .86$, and $\alpha = .86$ for the subscales of attitude, behaviour, and willingness to use QOL, respectively.

**Procedure**

All participants completed the questionnaire online using SurveyMonkey software and returned the survey electronically. Following approval from RMIT University Human Research Ethics Committee (HREC), participants were recruited from Australian hospitals that have transplant units. Transplant coordinators were notified of the study via an email containing an outline of the research and an electronic link to the questionnaire, and were requested to share the information with colleagues eligible to participate in the study.

An information sheet accompanying the questionnaire advised participants of the general purpose of the investigation and explained the reason they had been approached to participate (Appendix G). Participants were informed about the
voluntary nature of participation in the study, and the anonymous and confidential nature of participation through the collection of only non-identifiable information was explained.

**Results**

**Preliminary Data Analysis**

Data were analysed using SPSS version 18.0. While 34 of the original 41 participants (82%) provided a definition of QOL, a large number did not respond to the MD-QOL questionnaire items. Therefore, 17 cases that were missing more than 30% of data were removed prior to quantitative data analysis. The final sample for analysis, therefore, was 24 participants, including 16 nursing staff, 5 medical staff, and 3 allied health professionals.

Small amounts of missing data were replaced with the sample mean of variables, ensuring a full dataset. Two outliers were detected, however, these were retained in the data set as their inclusion did not alter final results. Normality of the MD-QOL subscales was assessed, with results of the Kolmogorov-Smirnov tests showing the behaviour and willingness scales satisfied normality requirements ($p > .05$) (Tabachnick & Fidell, 2007). The assumption of normality was violated on the MD-QOL attitude scale, however, this skew was expected as previous research has consistently indicated the high regard in which health professionals hold QOL.

**Descriptive Statistics**

Descriptive statistics and scale scores are presented in Table 6. The table also displays respondents’ mean scores from the groups of nursing, medicine, and allied health. Overall, health professionals reported a positive attitude to QOL, and willingness to use QOL information in clinical practice was also relatively high. However, self-reported use of QOL was lower than willingness, with the trend of
results indicating that medical health professionals reported the highest levels of use of QOL information in clinical practice. The mean and standard deviation pertaining to each item of the MD-QOL are presented in Table 7.

Table 6
**Descriptive Statistics of MD-QOL Scale**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>N</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude</td>
<td>24</td>
<td>48.21</td>
<td>5.24</td>
</tr>
<tr>
<td>Nursing</td>
<td>16</td>
<td>49.31</td>
<td>4.91</td>
</tr>
<tr>
<td>Medicine</td>
<td>5</td>
<td>46.40</td>
<td>4.51</td>
</tr>
<tr>
<td>Allied health</td>
<td>3</td>
<td>45.33</td>
<td>8.07</td>
</tr>
<tr>
<td>Willingness</td>
<td>24</td>
<td>29.17</td>
<td>6.38</td>
</tr>
<tr>
<td>Nursing</td>
<td>16</td>
<td>28.31</td>
<td>7.13</td>
</tr>
<tr>
<td>Medicine</td>
<td>5</td>
<td>31.40</td>
<td>5.55</td>
</tr>
<tr>
<td>Allied Health</td>
<td>3</td>
<td>30.00</td>
<td>2.65</td>
</tr>
<tr>
<td>Behaviour</td>
<td>24</td>
<td>26.79</td>
<td>9.07</td>
</tr>
<tr>
<td>Nursing</td>
<td>16</td>
<td>26.06</td>
<td>8.71</td>
</tr>
<tr>
<td>Medicine</td>
<td>5</td>
<td>31.40</td>
<td>11.40</td>
</tr>
<tr>
<td>Allied Health</td>
<td>3</td>
<td>23.00</td>
<td>6.24</td>
</tr>
</tbody>
</table>
### Table 7

**Descriptive Statistics of MD-QOL Items (N = 24)**

<table>
<thead>
<tr>
<th>MD-QOL Subscale and Item</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ATTITUDE</strong></td>
<td></td>
</tr>
<tr>
<td>1. Resources currently allocated to QOL should be used for basic transplant research</td>
<td>2.50 (1.06)</td>
</tr>
<tr>
<td>2. Using published QOL information is essential to good transplant patient care</td>
<td>3.50 (.59)</td>
</tr>
<tr>
<td>3. QOL is a subjective concept that cannot be quantified</td>
<td>2.50 (.83)</td>
</tr>
<tr>
<td>4. New QOL instruments are simply variations of previously ineffective tools</td>
<td>1.96 (.86)</td>
</tr>
<tr>
<td>5. Published QOL data are not useful for individual patient care</td>
<td>2.04 (.55)</td>
</tr>
<tr>
<td>6. The emphasis on QOL is a passing fad that will diminish over time</td>
<td>1.42 (.50)</td>
</tr>
<tr>
<td>7. QOL should be a required outcome measure for all Randomised Control Trials (RCTs) in transplant research</td>
<td>3.17 (.96)</td>
</tr>
<tr>
<td>8. The role of the health professional as an independent decision maker is jeopardized by the emphasis on QOL</td>
<td>2.12 (.54)</td>
</tr>
<tr>
<td>9. The emphasis on QOL is warranted in view of the lack of success in improving survival of transplant patients</td>
<td>2.75 (.85)</td>
</tr>
<tr>
<td>10. Adding QOL to RCTs will make transplant patients more willing to participate</td>
<td>2.29 (.91)</td>
</tr>
<tr>
<td>11. Adding QOL to RCTs in transplantation research will decrease health professional participation</td>
<td>2.00 (.78)</td>
</tr>
<tr>
<td>12. Most of my patients are willing to accept a poor QOL for even a small chance of receiving a transplant</td>
<td>2.29 (1.30)</td>
</tr>
<tr>
<td>13. Discussing QOL makes patients feel that they themselves are cared about, not just their disease</td>
<td>3.46 (.66)</td>
</tr>
<tr>
<td>14. My primary responsibility in treating transplant patients is to save lives</td>
<td>2.63 (.77)</td>
</tr>
<tr>
<td>15. Follow-up visits are primarily for monitoring the health of the patients, and not to assess QOL</td>
<td>2.08 (1.14)</td>
</tr>
<tr>
<td>16. Attention to QOL makes treatment decisions difficult</td>
<td>2.54 (.83)</td>
</tr>
<tr>
<td>17. In my opinion, prolonging survival with poor QOL is still a success</td>
<td>1.83 (.57)</td>
</tr>
<tr>
<td>18. The most important benefit of QOL is that one can ‘really treat the whole patient’</td>
<td>3.08 (.72)</td>
</tr>
<tr>
<td>19. When I initiate QOL discussions, my patients interpret this to mean that transplant is not possible</td>
<td>1.87 (.61)</td>
</tr>
<tr>
<td>20. Having to consider QOL sometimes reduces the medical professional’s ability to make optimal medical decisions</td>
<td>2.17 (.82)</td>
</tr>
<tr>
<td><strong>BEHAVIOUR</strong></td>
<td></td>
</tr>
<tr>
<td>21. I generally encourage my patients to complete QOL questionnaires</td>
<td>1.67 (1.55)</td>
</tr>
<tr>
<td>22. The information that QOL research provides about the relative impact of treatment options determines my treatment recommendation</td>
<td>1.79 (1.41)</td>
</tr>
<tr>
<td>23. I rely on my clinical experience to assess QOL</td>
<td>2.58 (.72)</td>
</tr>
<tr>
<td>24. I often read studies reporting QOL results</td>
<td>2.54 (.88)</td>
</tr>
<tr>
<td>25. I use published QOL results to modify my practice patterns</td>
<td>1.83 (1.24)</td>
</tr>
<tr>
<td>26. I am more likely to use toxicity information than QOL information when making treatment decisions</td>
<td>1.42 (1.25)</td>
</tr>
<tr>
<td>27. I use formal QOL questionnaires in my practice</td>
<td>1.67 (.80)</td>
</tr>
<tr>
<td>28. My decision to initiate QOL discussions does not depend on whether the circumstances are curative or palliative</td>
<td>2.71 (.99)</td>
</tr>
<tr>
<td>29. When I have to choose between prolonging survival or improving QOL, I usually attempt to prolong survival</td>
<td>1.54 (1.25)</td>
</tr>
<tr>
<td>30. When transplant is possible but unlikely, I intend to discuss QOL issues much less than when dealing with an incurable situation</td>
<td>1.50 (.86)</td>
</tr>
<tr>
<td>31. When a treatment offers a high chance of cure in conjunction with potential long-term survival, I downplay its negative impact on QOL</td>
<td>1.62 (.88)</td>
</tr>
<tr>
<td>32. I do not discuss QOL issues with my patients unless they ask about it first</td>
<td>1.96 (.86)</td>
</tr>
<tr>
<td>33. When I feel that QOL considerations are important in particular cases, I discuss QOL issues with patients even if they did not indicate an interest</td>
<td>2.58 (1.18)</td>
</tr>
<tr>
<td>34. I use QOL to justify not giving toxic treatments that are of questionable benefit</td>
<td>1.38 (.87)</td>
</tr>
</tbody>
</table>
WILLINGNESS

35. Even if QOL instruments had established validity and reliability, I would be reluctant to extrapolate the results to my patients 1.79 (.88)
36. Since quantifying QOL is problematic, I will not use QOL data 1.96 (.81)
37. Even if I were given more resources, I would not collect QOL information 2.00 (.66)
38. If collecting QOL data were less demanding of my resources, I would be more willing to collect it from my patients 2.62 (1.25)
39. I would not ask ill patients to complete QOL questionnaires 1.96 (.55)
40. If I were responsible for training health-care professionals, I would not use QOL data 2.88 (1.04)
41. Generally, I will spend my time on clinical care and leave QOL to others 2.50 (.83)
42. I do not plan to incorporate QOL data in my practice 2.04 (.62)
43. It is unlikely that I will increase my use of QOL in the care of future patients 2.92 (.83)
44. If QOL results were easier to understand, I would be more likely to use them 2.50 (1.10)
45. Even if published QOL results are shown to be clinically relevant, I am not likely to use them 1.88 (.61)
46. The more physicians are aware of the complexities of analyzing QOL, the less likely they will be to use them 2.00 (.98)
47. I would only be willing to use formal QOL assessment if required to do so by my institution or regulatory body 2.13 (.90)

The relationship between demographic factors and the QOL variables of attitude, willingness and behaviour were explored using Pearson product-moment correlation coefficients (see Table 8). All observed correlations between variables were well below .90, satisfying multicollinearity requirements. The only significant positive relationship between demographic and QOL variables was detected between gender and QOL attitude, \( r (24) = .44, p < .05 \). Inspection of the mean scores of attitude revealed that female health professionals (\( M = 49.65, SD = 4.72 \)) hold QOL in higher regard than male health professionals (\( M = 44.71, SD = 5.09 \)). However, this result should be interpreted with caution due to the large number of variables (type I error), and large sample size differences between genders.
Table 8
Intercorrelations Between MD-QOL Subscales and Health Professionals’ Demographic Variables (N = 24)

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. QOL attitude</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. QOL willingness</td>
<td>.21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. QOL behaviour</td>
<td>.11</td>
<td>.20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Gender</td>
<td>.44*</td>
<td>-.20</td>
<td>-.10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Age</td>
<td>.05</td>
<td>.06</td>
<td>-.18</td>
<td>-.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Organ type expertise</td>
<td>-.24</td>
<td>-.12</td>
<td>-.13</td>
<td>.03</td>
<td>-.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Patient population</td>
<td>-.22</td>
<td>.22</td>
<td>.06</td>
<td>-.19</td>
<td>.23</td>
<td>.03</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Year training completed</td>
<td>-.05</td>
<td>.09</td>
<td>.36</td>
<td>-.23</td>
<td>-.86**</td>
<td>.11</td>
<td>-.03</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Practice responsibilities</td>
<td>-.20</td>
<td>.10</td>
<td>.31</td>
<td>-.24</td>
<td>.20</td>
<td>-.38</td>
<td>.25</td>
<td>-.17</td>
<td></td>
</tr>
</tbody>
</table>

Note: **p<.01, *p <.05.
Defining Quality of Life

Thirty-four participants supplied definitions of QOL. Several themes emerged from the data, with pertinent themes grouped according to factors noted by health professionals as important to their understanding of QOL (Table 9). Interpretations of the term varied widely, with the majority of respondents emphasising patients’ enjoyment of life. One health professional purported QOL to be “a measure of ‘happiness’”, while others noted its relation to patients’ “ability to enjoy life” and “how much you enjoy life”.

Table 9
Health Professionals’ Definitions of Quality of Life (N = 34)

<table>
<thead>
<tr>
<th>Definitions</th>
<th>% of respondents who included this term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients’ enjoyment of life</td>
<td>53%</td>
</tr>
<tr>
<td>Patients’ performance status</td>
<td>41%</td>
</tr>
<tr>
<td>Related to illness or pain</td>
<td>32%</td>
</tr>
<tr>
<td>Defined by patients’ subjective judgment</td>
<td>17%</td>
</tr>
<tr>
<td>Multidimensional; mention of physical, psychological, and/or social wellbeing domains</td>
<td>17%</td>
</tr>
</tbody>
</table>

Note. Most responses included multiple descriptors of QOL.

Definitions related to pain or illness was also common, with several health professionals mentioning that a life of high quality is one “measured on the limitations the patient may experience due to their illness”, dependent on “limited capacity”, and related to “being healthy enough...” and “without the limitations of ill health”.

Functional status, including ability to work or attend school, was frequently commented upon. One health professional commented that QOL is defined by ability to “partake in... normal activities such as school, friendships and family life”, while others noted QOL to be related to doing “what’s required on a daily basis to sustain
life comfortably”, “being able to do the things in life... they want”, and “participation in desired activities.”

Fewer health professionals remarked on the subjective nature of QOL. One respondent noted that QOL is “dependent on the experiences of the patient”, while two others clearly stated QOL to be “a person’s subjective view of their life” and based on “an individual’s perception”. Another explained the potential of the subjective nature of QOL to cause discrepancies between individuals’ ratings of the impact of disability or ill health.

Health professionals in the current study infrequently noted the multi-dimensional nature of QOL. One described QOL as “physical, psychological and social wellbeing”, while another described QOL as “a measure of a person’s psychological and physiological health”. One made mention of the social domain by stating that QOL is “…their ability to participate within their own family and wider social circle and community”.

Attitude Towards Quality of Life

As summarised in Table 6, health professionals reported a generally positive overall attitude towards QOL, with the trend of results suggesting nurses hold a slightly higher level of regard towards QOL in comparison to medically trained health professionals, such as doctors. Respondents rejected the notion of QOL being a passing fad that will diminish over time. The vast majority disagreed with the statement that prolonging survival with poor QOL is still a success. Health professionals overwhelmingly agreed that using published QOL information is essential to good transplant care, yet a small percent of respondents believed published QOL data are not useful for individual patient care. Most held neutral views regarding the inclusion of QOL as an outcome measure in RCTs, reporting that it
would not decrease health professional participation but would not necessarily increase patient participation.

**Willingness to Use Quality of Life Information**

Results revealed mixed opinions among health professionals regarding willingness to use QOL information in clinical practice. Most (83.4%) stated they were unlikely to increase use of QOL data in the care of future patients. Half of respondents agreed that they would likely leave QOL issues to other health professionals, however, somewhat conversely 83.3% of health professionals stated that training of health professionals should include instruction on the use of formal QOL measures.

**Use of Quality of Life Information in Clinical Practice**

Results suggest that health professionals infrequently use formal QOL measures. Less than a quarter of the health professionals surveyed in the current study reported generally encouraging patients to complete QOL questionnaires, with most reported relying on clinical experience to assess QOL. While more than half stated that they often read studies reporting QOL results, fewer reported using QOL research to determine treatment recommendations, and even fewer used QOL findings to modify practice patterns.

**Perceived Barriers to Using Quality of Life Information**

Results of the MD-QOL imply that factors influencing health professionals’ use of QOL information in clinical practice include demands on resources, and difficulty in interpreting QOL results. Psychometric properties of QOL measures do not appear to be associated with the low frequency of use, with the majority of health professionals reporting that validity and reliability does not influence their intent to extrapolate research findings to patient treatment.
Discussion

While previous studies have sought to quantify the QOL improvements associated with transplantation and investigate the QOL experiences of transplant patients, the current study adopted a new perspective on QOL within transplantation by exploring health professionals’ views on QOL and surveying their use of QOL information in clinical practice. This exploratory study identified overall positive attitudes towards QOL and also pinpointed several possible barriers to health professionals using QOL information when treating transplant patients. The current findings inform possible methods to improve health professionals’ use of QOL information in clinical practice, and also point to several areas requiring further research.

Defining Quality of Life

Health professionals’ varied definitions of QOL reinforce its reputation as a nebulous concept. There were substantial differences in the responses regarding the key components of QOL, with respondents emphasising a range of parameters. Most did not include the key concepts of the WHO’s widely-used definition of QOL as a subjective view and a broad-ranging concept incorporating the person’s health, psychological state, level of independence, social relationships, and relationship to salient features of the environment (Orley & Kuyken, 1994).

Most health professionals emphasised patients’ enjoyment of life as an important aspect of QOL. The ability of transplant patients to function in capacities related to employment, school and leisure was closely tied to the idea of enjoying life, with many respondents including both constructs within their definition. Some commented on the importance of being able to complete daily tasks and participate in activities related to school and family life. The notion of independence that is central
to the definition of QOL is implicit in such remarks. Health professionals’ inclusion of patients’ level of functioning in the QOL definition lends support to previous research that reported doctors’ tendency to base QOL ratings on social indicators such as returning to work or attending school (Frost, et al., 2002; Skevington, et al., 2005). The ability to function is important to overall QOL, with a return to work, school or leisure activities potentially associated with improved psychological or physical functioning and social opportunities. Health professionals working with transplant patients may be especially likely to use performance status as a marker of QOL, as many transplant candidates are hospitalised and generally incapacitated prior to transplantation, making their return to everyday life a significant sign of recovery.

Many health professionals emphasised the relation of QOL to illness or physical pain. This is somewhat contrary to the definition of QOL as being based on more than simply the absence of ill health or disease (Murphy, et al., 2000). Health professionals’ emphasis on the importance of physical and illness related factors are congruent with previous research that identified doctors as reliant on ratings of physical health in their determination of QOL (Ekberg, et al., 2007; Janse, et al., 2004). While physical health is an important element of QOL, overemphasis on the domain on physical functioning may impede health professionals’ judgments about patients’ QOL, and may restrict their ability to assist patients to find meaning or enjoyment in life when illness or treatment results in physical problems such as immobility or restricted physical capacity.

Few respondents overtly commented on the subjective nature of QOL. Recognition of the subjectivity of QOL is important, as individuals’ experiences may impact upon illness or wellbeing and has the potential to inform treatment. Moreover, only a small number of health professionals noted the multi-dimensional nature of
QOL. Of respondents that did acknowledge it, several mentioned one domain while neglecting others. This may be a reflection of the specific expertise and experience of individual health professionals who normally consider one aspect of a patients’ life, such as doctors who concentrate on physical wellbeing or recovery following transplantation. However, a lack of consideration of the multi-dimensional nature of QOL may have implications for the way in which health professionals assess and consider QOL issues. Consideration of all aspects of QOL facilitates holistic care and may result in referral to other professionals for treatment of issues impacting on specific domains of QOL.

Definitions of the term QOL appear to be as subjective as the experience of QOL itself. Health professionals working in the field of transplantation considered a broad range of factors in defining QOL, including enjoyment of life, functionality, and illness and pain. Such inconsistent definitions of QOL may lead to substantial differences in the way in which QOL is assessed and discussed in clinical practice.

**Attitude and Willingness**

Findings of the MD-QOL in the current study suggest that health professionals place important value on the QOL issues of organ transplant patients. This was also evident in health professionals’ definitions of QOL, with consideration shown to many aspects of transplant patients’ lives and a general focus on assisting patients to achieve the best possible outcomes related to health, functional status, psychological wellbeing, and social and leisure activities. The positive attitudes expressed in this study are congruent with previous findings indicating that oncologists, stem cell transplant specialists and GPs have high regard for patients’ QOL issues (Bezjak, et al., 2001; Lee, et al., 2004; Skevington, et al., 2005; K. M. Taylor, et al., 1996). Such positive attitudes may be explained by health professionals’ general disposition to
help and care for ill people, and the inherent nature of healthcare as focused on the ability to improve health and wellbeing. Regardless of differences in the exact definition of QOL, health professionals’ general agreement on the importance of transplant patients’ ability to enjoy life and achieve a good standard of living reflects good patient care and an implicit recognition of QOL.

In terms of willingness to use QOL information, results of the current study suggest that health professionals are generally unwilling to alter the way in which they collect QOL information and seem satisfied to assess QOL informally rather than use QOL measures. This discrepancy between attitude and willingness has also been observed in previous research, with Morris, Perez, and McNoe (1998) finding that oncologists’ beliefs about the importance of collecting QOL data was not matched by actual collection levels. Possible reasons for this discrepancy are reviewed later in this chapter.

Use of Quality of Life Information in Clinical Practice

Despite positive attitudes towards QOL issues, health professionals reported infrequent use of QOL information and a clear preference for informal assessment over use of validated QOL measures. Respondents in the current study reported relying on clinical experience to assess QOL in an informal manner, with only a small number of health professionals using formal QOL measures in clinical practice. This is congruent with previous research, as oncologists and GPs also reported informal assessment of QOL (Bezjak, et al., 2001; Skevington, et al., 2005). This may be a reflection of health professionals’ training, as doctors generally use unstructured interviews while nurses usually engage in conversation to elicit information. Similarly, Frost and colleagues (2002) reported infrequent use of formal measures among oncologists, and GPs were found to have little knowledge of QOL measures
suitable for clinical practice (Skevington, et al., 2005). With only a small number of health professionals choosing to use formal measures to assess QOL, further research is needed to ascertain perceived benefits of such measures and the way in which the data is applied to clinical practice.

Previous research has warned against informal assessment of QOL due to inaccurate judgments and a lack of agreement between patient and health professionals on the patients’ QOL. However, another perspective may be to accept that an informal assessment of QOL is at its very least an acknowledgment of patients’ QOL issues. It is important to note that the use of QOL measures merely complements clinical judgment and does not replace it. Without information on the exact way in which data obtained from such measures is used between and within health professionals in clinical practice, it cannot be assumed that the use of formal measures necessarily constitutes better practice.

Most health professionals in the current study clearly stated that they are unlikely to use formal QOL measures despite good psychometric properties or encouragement from their institution; rather than force the use of such measures on unwilling professionals, another tact may be to thoroughly investigate the use of informal assessment of QOL to ascertain its usefulness. Providing health professionals with knowledge of the concept of QOL and informing them of targeted questions related to QOL that may be used in clinical interviews may be an adequate compromise for health professionals with expressed reluctance to employ QOL measures. Such information could be delivered via professional workshops or in the context of postgraduate training. However, while health professionals in the current study appeared to be unwilling to use formal measures of QOL, most advocated for the training of health professionals to include the use of such measures. This is
perhaps indicative of QOL not being regarding as a passing fad, and may show that health professionals expect QOL to be an increasingly important concept in the future of transplantation medicine.

More than half of the health professionals in the current study reported often reading studies pertaining to QOL within the transplant literature. This is higher than the readership of QOL studies among stem cell transplant physicians (Lee, et al., 2004) and oncologists (K. M. Taylor, et al., 1996), and may be a reflection of the large amount of QOL information published in relation to transplantation. While 58% of transplantation health professionals reported reading QOL studies, only 37.5% reported using such research to determine treatment recommendations. The reason for this disparity is unclear, however, the suggestion in previous research of results being difficult to interpret (Till, et al., 1994) also appears to apply to health professionals working with transplant patients, with many respondents in the current study stating that results are difficult to interpret. This may be a reflection of a lack of understanding of statistical analysis, as most health professionals receive only basic training in research. Further, the finding that health professionals continue to read studies that seem to have little utility to clinical practice is surprising and should be investigated in further research.

**Perceived barriers to using quality of life information.** The challenging and stressful nature of working as a health professional in the field of organ transplantation was evidenced by the majority of health professionals in the current study citing demands on resources as the main barrier to using QOL information in clinical practice. It appears that incorporating the use of QOL information may seem daunting to a health professional with an already heavy workload. However, Santana and colleagues (2010) showed that inclusion of QOL information in clinical practice
need not require additional time. The issue of extra time to administer, score and interpret results of QOL measures may be overcome by allowing administrative or other staff to collate data, in a similar to which pathology tests are relayed to health professionals. While Morris and colleagues (1998) found that oncologists believed that QOL evaluation should remain the responsibility of other health professionals, respondents in the current study largely disagreed with the statement that their ‘primary responsibility in treating patients is to save lives’, implying concern for general wellbeing of patients in addition to the prevention of illness or mortality. This may have been brought about by the multidisciplinary nature of the team on which transplant personnel work, as the distinct training and orientation of team members may influence the whole team.

**Interventions to Improve Use of Quality of Life Information**

Results of the current study suggest ways in which interventions may be used to promote the use of QOL information in transplantation clinical practice. With an apparent variation in the attitudes, willingness, and behaviours of health professionals to use QOL information, interventions to facilitate the use of QOL may benefit transplant patients by ensuring QOL issues are considered in clinical practice.

The majority of health professionals in the current study reported limited knowledge of QOL measures and reliance on clinical experience to assess QOL. Familiarisation with the concept of QOL may lead to increased consideration of it in clinical practice. This may be achieved through instruction on QOL issues being incorporated into the training of health professionals, a notion supported by the majority of health professionals in the current study. Previous research has shown that doctors’ communication skills are not necessarily innate and are indeed teachable, with coaching of communication skills leading to increased empathy, increased
appropriate responses to patients cues, and fewer leading questions (Lee, Back, Block, & Stewart, 2002). This lends credence to the idea that health professionals’ sensitivity to transplant patients’ QOL issues may be able to be shaped by training and intervention.

With regards to increasing the dissemination of research to clinical practice, results of the current study suggest that readership of QOL studies among transplant health professionals is already reasonably high. However, the application of research to clinical practice was observed to be relatively low. This may be increased by presenting research in a format that is easier for health professionals to understand, including using appropriate clinical language to express findings and reporting results in a succinct manner. Consulting health professionals in the design and application of research projects may assist in reducing the duplication of QOL studies and would ensure topics of interest are central to new research. While previous research has suggested obtaining assistance from health professionals in the development of QOL measures (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005), current results that showed little concern with reliability and validity of existing measures appear to contradict the need for development of new QOL assessment tools. Rather, providing health professionals with education and information about existing QOL measurement may be more appropriate.

Providing health professionals with the knowledge and tools to assess QOL must be accompanied by information regarding assistance for patients who are identified as experiencing QOL difficulties. This may include details of professionals to whom patients could be referred. With current and previous research (Morris, et al., 1998) showing that some health professionals regard QOL considerations as the responsibility of other professionals, easing the process of making an onward referral
may allay health professionals’ trepidation regarding assuming accountability for QOL factors that may be perceived as beyond clinical capacity or duty.

Limitations of the Current Study and Suggestions for Future Research

The results of this exploratory study indicate the viability of future research in this field. Replication or expansion of this preliminary investigation may enlighten researchers on the way in which health professionals use QOL and may result in an increased understanding of the impact of health professionals on transplant patients’ QOL. The relatively small and perhaps biased sample of the current study restricted analysis to data exploration; a more sustained and focused recruitment strategy may lead to a greater number of participants and the opportunity to conduct predictive statistical analysis. This would also allow for more thorough comparisons of the QOL attitudes and behaviour of, for example, medical staff and nurses, with such information useful for targeting interventions to improve use of QOL in clinical practice. Further, attrition was a major problem in this study that heavily impacted upon sample size. While most respondents provided a definition of QOL, many did not complete the MD-QOL. This may be a reflection of the time constraints on health professionals, and as such the use of a shorter questionnaire or selection of only pertinent questionnaire items should be considered in future studies with this population. The use of qualitative face-to-face interviews in future research may allow health professionals to better express their understanding of QOL and explore issues related to its definition and assessment.

The current study was the first to explore transplant health professionals’ definitions of the construct of QOL, adding to limited knowledge about the way in which the term is defined in clinical practice. However, it is should be noted that health professionals’ responses may only encapsulate the most pertinent aspects of
their knowledge of QOL. Future studies may opt to present respondents with a multiple choice list of variables associated with QOL, as respondents may find it easier to recognise a definition of QOL rather than recall, hence providing a more accurate description of their notion of QOL.

The Theory of Planned Behaviour (TPB) could be used in a larger scale study to explore the apparent discrepancy between health professionals’ overall positive attitude towards QOL and intent and behaviour associated with the use of QOL information in clinical practice with transplant patients (Ajzen, 1991). The TPB considers the role of attitude (positive or negative appraisal), subjective norm (perception of important others’ views), and perceived behavioural control (ease or difficulty of performing the behaviour) in relation to behaviour. The TPB has been used to test many health-related behaviours, including exercise participation, excessive alcohol consumption, and smoking cessation. It has also been applied to the behaviour of health professionals, including nurses’ ethical decision-making (Randall & Gibson, 1991), and has previously been posited as potentially useful to explain the unpredictable process of the uptake of research findings among health professionals (Eccles, et al., 2005). The worth of using the TPB to explain health professionals’ use of QOL information lies within its ability to inform a better understanding of the factors that may stop health professionals’ positive attitudes towards QOL being converted into use of QOL information in clinical practice. In turn, this information can be used to inform interventions at systemic and individual levels.

Further studies could also consider the impact of health professionals’ clinical practice on the QOL of transplant patients, and could corroborate the benefits of the use of QOL measures in transplantation medicine indicated by Santana and colleagues (2010). Patients’ perceptions of health professionals’ sensitivity to QOL issues could
also be investigated, as any intervention aimed to increase health professionals’ consideration of QOL is ultimately designed to assist patients. The concept of informal assessment of QOL also deserves further consideration. With health professionals generally unwilling to use formal QOL measures in practice, further information about the composition and content of informal assessment may inform training or information to be used to introduce a level of consistency in informal assessment.

**Concluding Comments**

In conclusion, the current study has demonstrated the usefulness of considering health professionals’ attitudes and behaviours related to QOL. Inclusion of this perspective on QOL is helpful in gaining a wider understanding of the concept of QOL within the field of organ transplantation. Findings of the current study suggest wide variation in the way in which health professionals consider and apply QOL information to clinical practice with transplant patients. The apparent disparity between positive attitudes toward QOL and minimal use of QOL information in clinical practice makes this area of research fertile for future research, with several areas of investigation and intervention possible to ensure transplant patients’ QOL issues receive adequate attention.
Chapter 4

Study 3 – Quality of Life and Family Functioning Following Pediatric Liver Transplantation

Study 3’s focus on pediatric transplant patients extends upon the theme of the QOL of organ transplant patients investigated in the previous two studies. The current study explores a new aspect of QOL by considering the impact of the transplantation process on pediatric liver transplant recipients and their families. Families are especially important to consider when investigating young transplant patients’ QOL, as children grow and develop within a family context, and post-transplantation recovery usually occurs in the family home rather than hospital. This chapter provides a brief summary of the literature relevant to pediatric liver transplantation, and provides a review of the limited research on family functioning in this field. Investigations of the relationship between QOL and family functioning in other clinical populations are also outlined. The intricate relationship between QOL and family functioning is explored, with a focus on adjustments made by families to accommodate children who have received liver transplants.

Pediatric Liver Transplantation

Since the first liver transplant on a three-year-old girl in 1963, vast advances in medical and surgical techniques have made liver transplantation standard treatment for children with end-stage liver disease (ESDL) (Otte, 2002). Long-term survival following liver transplantation in childhood is now the rule rather than the exception, with excellent patient survival rates of up to 82% at five years post-transplant (Heffron et al., 2010; Karim, Alex, Smith, & Hardikar, 2000). The medical improvements following pediatric liver transplantation are well established, and the primary aim of transplantation – to save lives – has clearly been met (Avitzur et al.,
Indeed, Kelly and Mayer (1998) state that pediatric transplantation has revolutionised the outlook for children with ESLD to the point that the primary problem in this field is now the shortage of donor organs.

There are substantial differences between pediatric and adult liver transplantation, including distinct underlying primary diseases, process of care, and surgical and infectious complications. Chronic liver disease during childhood affects the structural and functional development of the nervous system, and as a result advanced ESLD may disrupt cognitive processes such as the acquisition of reading and writing skills (Tarter, 1998). Age has been found to impact upon success of transplantation; adolescents recover more slowly than younger children but more quickly than adults, and optimal outcomes are associated with transplantation in children under 5 years of age (Cole et al., 2004; Kaufman, et al., 2010). Events surrounding transplantation and post-transplant recovery and care differ for pediatric patients due to unique growth and development issues, with ESLD and the need for transplantation associated with impaired growth. Furthermore, essential immunosuppressive medications, such as corticosteroids, have been found to adversely impact growth and mood among children and adolescents (Bucuvalas et al., 2003; Burra & De Bona, 2007).

With up to 15% of all liver transplants in Europe and the US performed on children younger than 18 years of age, many aspects of the long-term implications of pediatric liver transplantation have been widely investigated (Bucuvalas, et al., 2003). Early attempts to measure its success focused exclusively on medical outcomes and survival, and research focused on laboratory experiments to refine preservation techniques and immunosuppressive therapies that were integral to increasing the survival rates of young liver transplant patients (Starzl et al., 1968). In response to the
high mortality rate among small infants due to a shortage of appropriately sized donor organs, much early published research concentrated on technical aspects of transplantation procedures such as reduced size organs, split liver techniques and live donation (Burdelski et al., 1999; Kamath & Olthoff, 2010). Attention later turned to overcoming nutritional problems and assessment of pediatric patients’ cognitive functioning and academic ability (M. Maes, et al., 1997).

The benefits of pediatric liver transplantation are well documented. In addition to saving the lives of children who would otherwise die as a result of ESLD, liver transplantation in children results in decreased hospital visits, fewer hospital admissions, and less reliance on drug therapy (Manificat et al., 2003; Sokal, 1995; Stone, Beasley, Treacy, Twente, & Vacanti, 1997). The vast majority of children are able to return to school after liver transplantation, with a French study involving 280 pediatric liver transplant recipients finding that 69% experienced no delay in education while other children were less than a year behind same-aged peers (Fouquet et al., 2005). Pediatric patients’ experiences of psychological adaptation following transplantation has also been investigated, with one study concluding that infants return to full psychological functioning two years after transplantation (Stone, et al., 1997). Tornqvist and colleagues’ (1999) study on the long-term psychosocial adjustments of 146 pediatric liver transplant recipients concluded that children up to the age of 8 years reported no self-esteem or self-competency differences in comparison to healthy peers. However, adolescent boys who had received a transplant reported significantly lower self-worth and lower perceived athletic competence compared to non-transplant peers. Such research and recommendations of psychosocial interventions exemplify the continued shift away from pediatric liver transplantation being viewed as a purely medical phenomenon.
Pediatric Quality of Life

Quality of life is now widely accepted as a fundamental aspect of any medical treatment and is a basic criterion for evaluating the success of pediatric transplant procedures. Interpreted liberally within medical literature and everyday life, it is defined here as a multidimensional construct including physical health, psychological functioning, social functioning, and general wellbeing (R. Taylor, et al., 2005). It is also important to note that the construct of childhood QOL differs somewhat from that of adult QOL, with a child’s QOL incorporating the importance of peer relationships, school adjustment, and self-esteem as more salient factors in the lives of young people (Tarter, 1998).

A substantial amount of research has investigated the QOL of pediatric liver transplant patients, with Taylor and colleagues (2005) reporting that over 820 studies published between 1990 and 2003 specifically focused on the QOL of liver transplant patients from birth to 18 years of age. Numerous studies have consistently reported that QOL improves significantly after liver transplantation (Burra & De Bona, 2007). Avitzur and colleagues’ (2004) study of 35 pediatric recipients at 10-years post-transplant revealed self-reported QOL to be very good, despite ongoing health problems including 77% of participants having mild or moderate liver failure. Cole and colleagues (2004) reported significant QOL improvements during the first year post-transplant for all patients in the sample of 45 pediatric liver transplant candidates, noting that the most drastic QOL gains occurred in the first six months. Manificat and colleagues (2003) found that adolescent liver transplant recipients reported a very high QOL when completing a structured questionnaire, however, during qualitative interviews the children revealed concerns related to appearance, health, and difficulties with peer relations. It is unclear whether such concerns are
normative problems encountered during adolescence, or symptomatic of liver transplantation.

Zamberlan (1992) assessed the QOL of 20 liver transplant recipients aged between 5 and 8 years at 3 to 6 years post-transplant. The finding that children reported excellent QOL despite ongoing physical health problems is congruent with Avitzur and colleagues’ (2004) study, and substantiates QOL as a subjective experience that is usually independent of physical health or medical problems. An Australian study noted similar results and emphasised the potential for pediatric liver transplant recipients to enjoy excellent QOL (Chin et al., 1991).

Few studies have directly compared the overall QOL of pediatric liver transplant recipients with community-based samples of healthy children. Chin and colleagues (1991) used the Vineland Adaptive Behaviour Scales (VABS) to assess the QOL of 26 pediatric liver transplant patients at a minimum of 12 months post-transplant, and concluded the QOL of the clinical population to be equal to the normative sample. A later study of 56 children surviving liver transplantation for at least 2 years reported that although the group’s QOL was reasonably high, it remained significantly lower than the reference population (Midgley, Bradlee, Donohoe, Kent, & Alonso, 2000). While findings of a review of several studies concluded no statistically significant difference in the QOL of liver transplant and non-transplant children (R. Taylor, et al., 2005), limited research and inconsistent findings with this population point to the need for further research.

Limitations of previous research. The QOL of pediatric liver transplant patients has been extensively studied, however, a number of previous investigations featured flawed methodology that makes results difficult to reconcile. Several fail to consider the subjective nature of QOL and instead focused on overt signs of QOL.
such as medical wellness or the capacity to perform social, vocational and domestic tasks. For example, the finding that 82% of all pediatric liver transplant patients recipients are symptom free and lead entirely normal lives was wholly based on measures of medical health (Asonuma et al., 1998), while Burdelski and colleagues’ (1999) loose definition of QOL being associated with lack of morbidity contradicts WHO’s clear classification of QOL as comprising more than symptom-free survival (Murphy, et al., 2000). Kayler and colleagues’ (2002) claims of excellent QOL for most liver transplant recipients was based purely on physical health, and Sokal’s (1995) conclusion that children return to normal life and experience marked improvement in lifestyle following liver transplantation was entirely inferred from educational achievement and physical growth. In addition to broad and occasionally misleading definitions of QOL, varying research methods, measures and study designs make results difficult to reconcile. In addition to the limited qualitative research conducted in this area, QOL related to transplant-specific factors has also lacked investigation.

**Transplant-Related Quality of Life**

Receiving a liver transplant is a traumatic event for a child, with the transplantation process invariably involving lengthy hospital admissions, ongoing medication, invasive procedures, and great uncertainty about health and longevity. Despite the unique experiences of pediatric transplant patients, most studies continue to employ generic QOL measures to explore differences from pre- to post-transplant or compare their QOL to non-transplant normative samples. Only a small number of studies have investigated transplant-specific factors associated with QOL. Weissberg-Benchell and colleagues (2010) identified several transplant-specific factors relevant to the QOL of pediatric recipients of liver, kidney, kidney, heart and small bowel
transplantation through focus groups and interviews with pediatric transplant patients and their families. Transplant-specific factors found to be important to pediatric transplant recipients’ QOL included medication side effects, difficulties with medication regimen, social activities, pain and hurt, worry, treatment anxiety, and concerns about physical appearance. A study of 342 American pediatric transplant recipients, including 90 liver transplant recipients, revealed children experience optimal QOL related to medication regimen, and worst QOL related to pain and hurt (Weissberg-Benchell, et al., 2010).

Zamberlan (1992) found that school-aged children who had received a liver transplant reported difficulties with socialisation skills, feelings of loneliness, and concerns regarding ability to maintain peer relationships. Interestingly, the children reported the transplant experience as largely positive, recalling a greater amount of happy than unhappy memories of their hospital stay. Wise (2002) interviewed nine liver transplant recipients between the aged of 7 and 15 who were at least one year post-transplantation with the objective of investigating the overall and everyday experiences of the children in relation to liver transplantation. Themes arising from this qualitative study included difficulty with peer relationships, with participants reporting a desire to fit in with peers and not have attention drawn to their status of transplant recipients. The children also reported that unease with physical differences such as increased hair growth, jaundice, and scarring, led to attempts to minimise or hide physical differences from peers. Medication regimen was not a concern, with children reporting ease with integrating medications into their daily routine. Pain and hurt concerns were mostly focused on procedural pain such as needles for ongoing blood tests, with most children unable to recall details of surgical pain. Children also perceived their parents to be overprotective and hyper vigilant in the post-
transplantation period, and reported this to be incongruent with their desire for normalcy in social, academic and home environments. A recent qualitative study investigating adolescent liver transplant recipients’ QOL perception identified a similar focus on peer relationships and ease with daily medication regimen (R. M. Taylor, Franck, Dhawan, & Gibson, 2010). Adolescents were also concerned with ongoing health and wellness and the impact of transplantation on their education and employment prospects. Distinct from younger children interviewed in other qualitative studies (Wise, 2002; Zamberlan, 1992), adolescents reported difficulties communicating with medical professionals, and increased anxiety was associated with not feeling fully-informed about the state of their health, ESLD, and transplantation. Further to transplant-related factors, family functioning has also been posited as important to the QOL of children who have received liver transplants (Alonso et al., 2008; Alonso et al., 2003).

**Family Functioning**

Family functioning in the present study is conceptualised as the frequency of disruption to usual family routines, effectiveness of family communication and problem solving, family cohesiveness, and how well family members get along (Fredericks, et al., 2007). Weisner, Matheson, Coote, and Bernheimer (2004) contend that engagement with consistent family routines is integral to a child’s wellbeing. Regular family routines teach children about individual and familial patterns of behaviour while establishing important developmental and social pathways. This offers opportunities of positive psychological experiences that contribute to self-esteem, such as pleasure, attachment and competence.

Focusing on the routines of a family provides valuable insight into the functioning of a family (Weisner, et al., 2004). A family’s ability to maintain daily
routines in the face of major crisis, such as a child undergoing liver transplantation, is an important indicator of family strength, cohesion and capacity to cope with stressful life events. Moreover, an analysis of family routines may inform areas of potential intervention and has meaningful implications for policy and clinical practice. As Bernheimer and Weisner (2007) state, it is futile to introduce an intervention that is incongruent with the daily routines of a family. Weisner and colleagues (2004) suggest that routines affect the wellbeing of all family members, with parents having to balance their goals and wishes for themselves and their children with available resources and limitations in a way that is congruent with their personal, cultural, and moral ethos. The competing interests and individual needs of children, common in families of pediatric liver transplant recipients, may interfere with parents’ capacity to establish regular family routines.

Frequent change and unpredictable daily routines are unhelpful for children, and compromise the sustainability of family life (Weisner, et al., 2004). Gallimore, Coots, Garnier and Guthrie (1996) emphasised the importance of studying the functional accommodations made to sustain daily routines, and found that accommodations made by families of children with developmental delays are consistently associated with specific behavioural characteristics among children. Accommodation is defined as the adjustments made by a family in response to the demands of daily life, and include actions taken, avoided or delayed in an attempt to sustain a family routine (Gallimore, et al., 1996).

Family functioning of pediatric transplant patients. The QOL of pediatric liver transplant patients has received widespread attention, yet the wellbeing of their families is less often investigated, leading Alonso and colleagues (2003) to call for better assessment of the effect of transplantation on family functioning. Following a
period of recuperation in hospital, most children return to the family home within weeks of transplantation. Despite the important role of the family and the home environment in the short- and long-term recovery after transplantation, there has been little investigation of the relationship between family functioning and pediatric transplant patients’ QOL. In addition to the emotional consequences of an ESLD diagnosis and undergoing the transplant process, parents must quickly begin to accommodate their ill child by reshaping daily family routines and reorganising resources, family activities, goals, and priorities (Weisner, et al., 2004). An understanding of the family environment to which children return following transplantation is integral, as a child’s understanding of health and wellbeing is shaped within the family context (Manificat, et al., 2003).

An early study investigating the family routines of 35 pediatric kidney transplant recipients concluded that most families returned to normal family functioning within a year of transplantation. The study also found that diminished self-esteem among children was common, and children and their families feared organ rejection (Korsch et al., 1973). Despite this initial interest in the family functioning of transplant patients, several decades passed before any further research in this field was conducted.

Other family-related factors of pediatric transplant patients have also been researched, including family cohesion and the impact of transplantation on marital relationships. Some studies report cohesion among family members of pediatric transplant patients to be slightly higher than the general population (Alonso, et al., 2003), while others cite no difference (Fredericks, et al., 2007). Family cohesion has been shown to improve with time elapsed after transplantation (Cole, et al., 2004), and low levels of family cohesion are also associated with medication non-adherence,
which in turn relates to a significant increase in rejection episodes and hospital admissions (Fredericks, et al., 2007; Griffin & Elkin, 2001). The marital relationships of parents of pediatric liver transplant patients has also been studied: Kennard, Petrik, Stewart, Waller, and Andrews (1990) found that children from intact marriages were more likely to successfully adapt following transplantation, while Zitelli and colleagues (1988) reported that more than a third of divorced or separated parents of pediatric transplant patients claimed the stress of raising a chronically ill child contributed to marital discord. However, the results of this early study could be indicative of the lower survival rates and contemporary progress in pediatric transplantation, as substantial medical advances have been made since the 1980s.

Two prominent studies have investigated separate aspects of the functioning of families of pediatric liver transplant patients. Alonso and colleagues (2003) assessed the frequency of activities engaged in by the families of 53 pediatric liver transplant recipients, concluding that transplant families participated in limited type and frequency of family activities compared to a community sample. Somewhat conversely, a larger multi-centre study of 102 patients at two years post-transplantation reported that transplant families do not experience increased levels of family dysfunction (Alonso, et al., 2008).

Several other studies have also investigated elements of family functioning. Fredericks, Lopez, Shieck, and Opipari-Arrigan (2007) measured the functioning of pediatric liver transplant patients’ families as part of a larger investigation of medication adherence and parental stress following transplantation. Defining family functioning in terms of cohesion among family members, results revealed no significant differences in the family functioning of transplant patients compared to published norms or children experiencing other medical illnesses. Similarly,
LoBiondo-Wood, Williams, and McGhee (2004) found no significant change in overall functioning of families of pediatric liver transplant patients from pre- to post-transplant, as measured by the family’s adaptability to change. Further, Stone and colleagues (1997) concluded that families of children five to ten years post-transplantation were participating in normal activities of daily living. The study also found that parents were pursuing hobbies and held normal levels of employment. Sokal (1995) found that children and families return to a normal life after transplantation and enjoy a markedly improved lifestyle, however, these findings should be interpreted with caution as the study did not feature any formal measurement of family functioning.

Parents’ experiences of pediatric transplantation may also provide insight into family functioning. In a descriptive study, Gold, Kirkpatrick, Fricker, and Zitelli (1986) drew on comments from parents attending a hospital-based support group to investigate the impact of the transplantation process on parents of children who had received heart and liver transplants. Parents described transplantation as far from a panacea, defining it as a disease just like ESLD which impacts upon family functioning. The main psychosocial issues reported by parents were financial difficulties, adapting to new parenting roles, fear of organ rejection or death, and readjustment to family structure. Rodrigue and colleagues (1997) suggest that the daily adjustments required to accommodate a child post-transplantation may lead to severe parental depression and anxiety, especially for mothers who are most often primary caregivers. Mothers continue to experience high levels of parenting stress several months after transplantation, with demanding tasks such as dealing with medication noncompliance, arranging medical follow-up appointments, and enforcing
physical activity restrictions while also attending to the needs of other children (Rodrique, et al., 1997).

Parents of pediatric liver transplant patients also report stress related to ongoing medical care, disruption to family routine, and ongoing anxiety related to their child’s health (Alonso, et al., 2008). Similarly, an earlier study found significant amounts of parental stress among mothers of pediatric transplant recipients, and recommended psychosocial follow-up with parents for at least five years following transplantation (LoBiondo-Wood, et al., 2004). Parents have also been identified as playing a crucial role in maximising medication adherence among pediatric patients (Lurie et al., 2000), and parents’ readiness for their child’s transition from hospital to home has been found to be associated with medication adherence, parent coping difficulty, and adherence to medical follow-up (Lerret & Weiss, 2011). This implicit connection between parent wellbeing and patient health behaviours further exemplifies the need to investigate family functioning, as parents are primarily responsible for the structure and organisation of family routines.

**Family Functioning and Quality of Life**

Previous research focusing on children with disabilities has identified an important relationship between QOL and family functioning (Gallimore, et al., 1996; Weisner, et al., 2004). However, this relationship has not been studied within the population of pediatric transplant patients, despite several studies focusing on the separate constructs of QOL and family functioning, as detailed in this chapter. Most notably, Alonso and colleagues (2003; 2008) investigated factors influencing the QOL and family functioning of pediatric liver transplant recipients, yet the association between the two variables was not directly tested.
While not explored within the pediatric transplant literature, the relationship between QOL and family functioning in other clinical populations has received a modicum of attention. A study investigating the QOL and psychosocial factors of adolescents with implantable cardioverter-defibrillators reported a significant correlation between QOL and family functioning, with the authors concluding that the adolescents’ QOL is more strongly related to family functioning than illness severity (DeMaso et al., 2004). An Australian study investigating the QOL of adolescents with cystic fibrosis also found that family characteristics of cohesion, conflict, and expressiveness to have a significant impact on QOL (Szyndler, Towns, van Asperen, & McKay, 2005). However, an investigation of 236 children with asthma failed to identify a significant relationship between asthma-related QOL and family functioning, but an association between family functioning and the child’s psychological wellbeing was found (Sawyer et al., 2001). No relationship between family functioning and QOL was found in a study of 52 adolescents with diabetes (Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998). Given these inconsistent findings, further investigation of the relationship between QOL and family functioning is warranted.

**Aims and Research Questions of the Current Study**

The aims of the current study were to investigate the QOL of liver transplant recipients, the way in which families adjust to accommodate children following liver transplantation, and to explore the relationship between family functioning and QOL. Five research questions were posed:

1. Does the QOL of children who have received liver transplants differ from children in the community?
2. In which specific QOL areas do pediatric liver transplant recipients experience relative deficits?

3. Does the family functioning of pediatric liver transplant recipients differ from other children in the community?

4. Do family functioning and QOL improve with time-elapsed post-transplantation?

5. What is the relationship between family functioning and QOL of pediatric liver transplant recipients?

Method

Participants

The parents/caregivers of 65 children participated in the study, representing two groups: families of pediatric liver transplant recipients \((n = 32)\), and families of non-transplant children \((n = 33)\). Most respondents were mothers \((61.5\%)\) or fathers \((30.8\%)\), with a small number of grandparents responding. The average age of transplant recipients was 10.10 years \((SD = 3.62)\), with 52% males and 48% females comprising the transplant group. Recipients were between 1.1 year and 12 years post-transplantation \((M = 5.31, SD = 3.44)\). Biliary artesia was the most frequent underlying disease precipitating transplant \((52\%)\), while other diagnoses included alpha-1 antitrypsin deficiency, omithine trans-caramylase (OTC) deficiency, fulminant liver failure, and metabolic liver disease. The average number of overnight hospital stays for the transplant group in the immediate six months prior to the study was 1.20 \((SD = 2.27)\). The non-transplant group of children was slightly younger than the transplant group \((M = 9.61, SD = 3.57)\) and comprised 65% males and 35% females.
Materials

**PedsQL™ 3.0 Transplant Module Parent Report.** The QOL of transplant recipients was measured using the PedsQL™ 3.0 Transplant Module Parent Report (Weissberg-Benchell, et al., 2010). Forty-six items encompass eight scales (with original and current study Cronbach’s α in parentheses, respectively): barriers to medical regimen adherence (.94; .85), medication side-effects (.77; .54), social relationships and transplant (.95; .84) physical discomfort (.71; .71), worries related to health status (.91; .95), anxiety regarding medical procedures (.88; .92), impact of transplant on appearance (.80; .81) and communication with medical personnel and others about transplant (.92; .87). An overall QOL rating is also derived (.94; .93).

**PedsQL™ 4.0 Parent Report for Children – Generic Core Scales.** The QOL of non-transplant children was measured using the PedsQL™ 4.0 Parent Report for Children – Generic Core Scales (Varni, Seid, & Kurtin, 2001). Twenty-three items assess physical, emotional, social and school functioning, in addition to providing an overall QOL rating. Original internal consistency and reliability of the measure was high (.90). Cronbach’s α for overall QOL in the current study on overall QOL was low (.69). This measure has been found to correlate highly with the PedsQL 4.0 Transplant Module (Weissberg-Benchell, et al., 2010), and was therefore deemed appropriate to provide comparisons between the groups.

**Family Accommodations Questionnaire.** The Family Accommodations Questionnaire (FAQ) (Gavidia-Payne & Tainsh, 2007) was used to measure the extent to which families modify or adjust routines to accommodate their children. The FAQ was developed on the basis of an interview schedule by Gallimore and colleagues (1996), with most previous research investigating family accommodations being of a qualitative nature. The questionnaire was completed by both transplant and non-
transplant families, with respondents asked to rate their agreement to each statement on a five point Likert scale. The FAQ comprises 27 items related to nine areas in which families may make adjustments to accommodate children (with Cronbach’s $\alpha$ for the current study in parentheses): work (.76), services (.70), the family home (.82), domestic workload (.86), childcare tasks (.60), assistance from others (.25), child peer groups, marital roles (.36), and parent information (.67). A total family functioning score is also derived (.90); higher scores indicate more adjustments to family routine, with a greater score reflecting less optimal family functioning.

**Qualitative comments.** In addition to completing the QOL and family functioning measures, parents were invited to share their experiences regarding their child’s liver transplantation via a comments page included in the questionnaire pack.

**Procedure**

Approval for this study was obtained from the Royal Children’s Hospital (RCH), RMIT University, and the Department of Education and Early Childhood Development HRECs. All potential participants received a plain language statement detailing the purpose of the research, its aims, and the reason they had been approached to participate. An explanation of the voluntary nature of participation and participants’ right to withdraw from the study was also included. Written informed consent was obtained from parents/caregivers of all children and returned to the research team via reply-paid postage.

Parents of children aged between 3 and 16 years who received a transplant at RCH’s Department of Gastroenterology between 1995 and 2010 were identified via the hospital’s Clinical Lookup and Results Acknowledgement (CLARA) medical records system. Eligible parents were mailed a letter introducing the study (Appendix H), followed two weeks later by a pack comprising an information sheet (Appendix
A follow-up phone call was made to families who did not return the questionnaire within three weeks. A total of 55 transplant families were invited to participate, with a return rate of 32 respondents (58%). Patient confidentiality and anonymity were assured by all communication with participants and return of surveys being managed by a member of the research team who has access to patient records as part of her usual employment at RCH. Any identifying information, such as names, was removed from the questionnaires prior to data analysis, and consent forms were stored in a separate location from questionnaires. In accordance with the procedure of the RCH HREC, all families who were invited to participate in the study received a plain-language summary of results at the conclusion of the study (Appendix L).

Families of non-transplant children were recruited in collaboration with a separate research project conducted through RMIT University. Following approval from school principals of primary and secondary schools, packs comprising a plain language statement (Appendix M) and set of questionnaires (Appendix N) was distributed to parents inviting them to participate in the study. Families from the non-transplant group who reported a serious childhood illness were not eligible to participate. Thirty-three of seventy questionnaire packs were returned, yielding a 47% response rate.

Results

Preliminary Data Analysis

Data were analysed using SPSS version 18.0. Prior to data analysis being performed, two cases from the transplant group were removed from the sample, as they were missing more than 30% of data on at least one scale. Missing values of
remaining cases were replaced with the sample mean for that variable, thus providing a complete dataset.

Examinations of the assumptions of normality, homoscedasticity and linearity were conducted on the QOL variables. Diversion from normality was detected among the following variables: healthy population physical QOL, healthy population social QOL, healthy population social QOL; transplant medicines, physical discomfort, worries related to health status, anxiety regarding medical procedures, impact of transplant on appearance, and communication with medical personnel and others about transplant. Variables were not transformed, as variables primarily used for analysis, including overall QOL for both transplant and healthy populations, satisfied normality requirements, and skewness was expected among variables as previous research has identified QOL to generally be rated high among clinical and healthy populations.

Examination of the family functioning scores also revealed deviations from normality amongst all variables with the exception of total score, and subscales for work, services and marital roles. Transformation did not improve normality of the skewed variables, and no further alterations to data were made as skewness of variables was expected and the analyses used are robust to normality violations. Several multivariate outliers were identified (Mahalanobis’ Distance = \( p < .05 \)), however, the outlying cases were retained in the dataset as the original and 5% trimmed means were very similar. No multicollinearity or singularity between variables was detected.

Qualitative data provided via written comments from parents was analysed for common themes and given a descriptive label. As less than half the parents from the relatively small sample size provided comments, it was deemed suitable to manually
identify common themes in place of using formal qualitative data analysis techniques (Pallant, 2002).

**Quality of Life Differences Between Transplant and Non-Transplant Children**

An independent samples t-test was conducted to compare the overall QOL scores of transplant and non-transplant children. Equal variances were not assumed (Levene’s <.001). Results indicated a statistically significant difference in QOL scores between transplant ($M = 77.79, SD = 13.45$) and non-transplant children ($M = 87.32, SD = 6.16$), $t(39.82) = -3.56, p = .001, \eta^2 = .06$.

**Transplant Patients’ Quality of Life and Transplant-Specific Quality of Life**

Caregiver reports of their child’s QOL varied across transplant-specific QOL areas. Figure 6 represents caregivers’ ratings of their child’s experiences with transplant-related QOL variables. Higher mean scores on each subscale indicate better QOL related to that area. The 95% confidence interval corresponding to each variable indicates the variance of responses to the subscale, with smaller confidence intervals indicating less variability. Scores were highest for QOL associated with medicine-related side effects ($M = 90.93, SD = 10.68$) and lowest for QOL associated with anxiety about treatment ($M = 67.29, SD = 27.84$).
Correlational analyses, summarised in Table 10, indicated significant and strong positive relationships between overall QOL and pediatric liver transplant recipients and several QOL areas, as measured by the PedsQL Transplant Module. Significant positive associations were found between QOL and all variables except for communication, indicating that overall QOL increases as scores rise in any one of these transplant-specific areas. Conversely, patients’ ease of communication, such as being able to understand doctors’ explanations or ease with telling others about the transplant, was not associated with QOL benefits.
Table 10
*Intercorrelations Between Transplant Patients’ Quality of Life and Quality of Life Variables (N = 30)*

<table>
<thead>
<tr>
<th>QOL</th>
<th>MI</th>
<th>MII</th>
<th>TO</th>
<th>PH</th>
<th>W</th>
<th>TA</th>
<th>PA</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicines I (MI)</td>
<td>.68**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicines II (MII)</td>
<td>.64**</td>
<td>.29</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transplant and others (TO)</td>
<td>.87**</td>
<td>.54**</td>
<td>.53**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain and hurt (PH)</td>
<td>.58**</td>
<td>.21</td>
<td>.30</td>
<td>.56**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worry (W)</td>
<td>.78**</td>
<td>.37*</td>
<td>.54**</td>
<td>.61**</td>
<td>.48**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment anxiety (TA)</td>
<td>.57**</td>
<td>.17</td>
<td>.45*</td>
<td>.32</td>
<td>.16</td>
<td>.45*</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Physical appearance (PA)</td>
<td>.64**</td>
<td>.36</td>
<td>.30</td>
<td>.64**</td>
<td>.38*</td>
<td>.36*</td>
<td>.25</td>
<td>-</td>
</tr>
<tr>
<td>Communication (C)</td>
<td>.19</td>
<td>.17</td>
<td>-.21</td>
<td>.16</td>
<td>.18</td>
<td>-.23</td>
<td>.06</td>
<td>.20</td>
</tr>
</tbody>
</table>

*Note:* **p < .01.  *p < .05.

**Family Functioning of Transplant and Non-Transplant Children**

A significant difference was detected in the overall functioning of transplant and non-transplant families, as measured by the FAQ (Gavidia-Payne & Tainsh, 2007), \( t(61) = 2.28, p = .026 \). The magnitude of the difference was moderate (\( \eta^2 = .07 \)). More alterations to family routines to accommodate children were reported by transplant families (\( M = 68.93, SD = 18.25 \)) in comparison to non-transplant families (\( M = 59.15, SD = 15.78 \)).

Mean scores on the FAQ subscales, summarised in Table 11, indicate that transplant families made more adjustments in all areas except for seeking information related to caring for children. However, a one-way between groups MANOVA revealed the only difference to reach statistical significance, using the Bonferroni adjusted \( \alpha \) level of .006, was childcare, \( F(1, 61) = 8.18, p = .006; \eta^2 = .19 \). As detailed
in Table 11, transplant families reported making significantly more adjustments to childcare arrangements than non-transplant families.

Table 11
Two-Way Multivariate Analysis of the Functioning of Transplant and Non-Transplant Families

<table>
<thead>
<tr>
<th>FAQ subscale</th>
<th>df</th>
<th>df error</th>
<th>F</th>
<th>$\eta^2$</th>
<th>p value</th>
<th>Transplant M (SD)</th>
<th>Non-transplant M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work</td>
<td>1</td>
<td>61</td>
<td>1.90</td>
<td>.030</td>
<td>.173</td>
<td>2.87 (1.04)</td>
<td>2.54 (.84)</td>
</tr>
<tr>
<td>Services</td>
<td>1</td>
<td>61</td>
<td>2.26</td>
<td>.036</td>
<td>.138</td>
<td>2.52 (1.08)</td>
<td>2.12 (1.04)</td>
</tr>
<tr>
<td>Home &amp; community</td>
<td>1</td>
<td>61</td>
<td>6.42</td>
<td>.095</td>
<td>.014</td>
<td>2.07 (.94)</td>
<td>1.54 (.69)</td>
</tr>
<tr>
<td>Domestic workload</td>
<td>1</td>
<td>61</td>
<td>7.56</td>
<td>.110</td>
<td>.008</td>
<td>2.21 (1.08)</td>
<td>1.55 (.80)</td>
</tr>
<tr>
<td>Childcare</td>
<td>1</td>
<td>61</td>
<td>8.18</td>
<td>.118</td>
<td>.006*</td>
<td>2.63 (1.20)</td>
<td>1.85 (.98)</td>
</tr>
<tr>
<td>Assistance</td>
<td>1</td>
<td>61</td>
<td>5.33</td>
<td>.080</td>
<td>.024</td>
<td>2.45 (.90)</td>
<td>1.92 (.90)</td>
</tr>
<tr>
<td>Child peer groups</td>
<td>1</td>
<td>61</td>
<td>4.99</td>
<td>.076</td>
<td>.029</td>
<td>2.73 (1.41)</td>
<td>2.03 (1.07)</td>
</tr>
<tr>
<td>Marital roles</td>
<td>1</td>
<td>61</td>
<td>4.65</td>
<td>.071</td>
<td>.035</td>
<td>3.38 (.80)</td>
<td>2.97 (.73)</td>
</tr>
<tr>
<td>Parent information</td>
<td>1</td>
<td>61</td>
<td>3.19</td>
<td>.050</td>
<td>.079</td>
<td>2.70 (.77)</td>
<td>3.05 (.80)</td>
</tr>
</tbody>
</table>

*significant at Bonferroni adjusted level of .006.

Post-Transplantation Associations between Family Functioning and Quality of Life

Correlational analyses were used to investigate improvements in family functioning and QOL over time post-transplantation. No relationship was detected between time since transplant and QOL, $r (n = 30) = -.311, p = .094$. To further investigate the relationship between time since transplant and QOL, the transplant recipients were separated into two groups according to time elapsed since transplantation (1-6 years, 7-12 years). Results of an independent t-test showed no significant differences in the QOL of the 1-6 years group ($M = 79.42, SD = 14.13$) and the 7-12 years group ($M = 73.30, SD = 10.93$), $t (28) = 1.10, p = .28, \eta^2 = .008$.

A moderate positive correlation was found between family functioning and QOL, $r (n = 30) = -.57, p = .01$, indicating that less adjustments to family routines are associated with QOL improvements. Family functioning improves with time since
transplant, \( r (n = 30) = .395, p = .031 \). Family functioning and QOL ratings derived from this small sample are depicted in Figure 7.

**Figure 7.** Pediatric liver transplant patients’ post-transplantation QOL and adjustment to family routine

**Qualitative Data**

Parents’ qualitative responses are summarised in Table 12. Several parents commented on the improvement in family functioning from pre- to post-transplantation, noting that their responses would have been vastly different at pre-transplantation. Parents also commented on employment difficulties and the impact of the transplantation process on the parents’ marriage. Anxiety about ongoing medical problems was exemplified by a father’s concerns of his son having to return to the waitlist should he require another transplant. Two parents commented on how
transplantation at an early age was associated with good outcomes. Lastly, appreciation of the care provided by RCH was also expressed.
Table 12

*Qualitative Responses From Parents of Pediatric Liver Transplant Recipients.*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Respondent</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre- to post-transplant family functioning</td>
<td>Mother of 8-year-old girl</td>
<td>“…prior to the transplant it was a very different story and under the family accommodations questions almost all answers would have been at the other end of the scale.”</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>“Had we been responding back [pre-transplant] our responses would have been swayed towards the extreme end of the spectrum, as medical outlook was quite dire months on end.”</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>“We dropped everything to care for her in the same way most liver families do.”</td>
</tr>
<tr>
<td>Employment</td>
<td>Mother of 13-year-old boy</td>
<td>“I myself is a single parent who brought [child] up, from the age of 4 till transplant, and still now at the age of 13. I gave up work for two years after transplant and went through 5 rejections.”</td>
</tr>
<tr>
<td></td>
<td>Father of 14-year-old boy</td>
<td>“My wife can’t work (14 years) due to our son’s illness. I have to work two jobs – one full time, one part time.”</td>
</tr>
<tr>
<td>Marital problems</td>
<td>Mother of 4-year-old boy</td>
<td>[Child]’s diagnosis was the trigger for marriage breakdown.”</td>
</tr>
<tr>
<td>Anxiety about ongoing medical problems</td>
<td>Father of 14-year old boy</td>
<td>“If we have to go through another liver transplant give us some concessions in regarding to waiting list priorities.”</td>
</tr>
<tr>
<td></td>
<td>Mother of 4-year-old boy</td>
<td>“[Child] has issues with sleeping, lack of appetite and eczema.”</td>
</tr>
<tr>
<td></td>
<td>Mother of 12-year-old girl</td>
<td>“…as always the day of transplant and following months are still very raw in our minds.”</td>
</tr>
<tr>
<td>Transplantation at early age</td>
<td>Mother</td>
<td>“[Child] had his transplant at 18 months old in 2002. Therefore it’s been quite a while and he has learned that this is part of his life.”</td>
</tr>
<tr>
<td></td>
<td>Father of 8-year-old boy</td>
<td>“No bother, [child] is only 8 and he had it when he was 10 months old so he doesn’t really know any different.”</td>
</tr>
<tr>
<td>Experience with hospital</td>
<td>Mother of 5-year-old girl</td>
<td>“My experience with RCH was a positive one – the specialists go above and beyond their duties and all supporting staff have been amazing in their care, duties and professionalism. Social workers give great advice and often organise and assist you in organizing respite etc to make the continuing journey easier.”</td>
</tr>
<tr>
<td></td>
<td>Father of 12-year-old girl</td>
<td>“Have the support group run by the hospital.”</td>
</tr>
</tbody>
</table>
Discussion

The QOL and family functioning of liver transplant recipients has thus far been investigated as separate concepts. A number of studies have examined the QOL of young liver transplant patients, with less attention paid to role of family in the post-transplantation experiences of children. With these areas of previous research in mind, the aim of the current study was to investigate the relationship between the QOL and family functioning of pediatric liver transplant recipients. Comparisons of the QOL of pediatric transplant recipients and other children were also investigated. In order to achieve a better understanding of the unique experiences of pediatric transplant recipients, the current study also explored the transplant-specific factors associated with the QOL of young liver recipients. Findings that the transplantation process is associated with relative deficits in both QOL and family functioning suggest a need to better understand factors related to the family life of transplant recipients.

Quality of Life of Transplant and Non-Transplant Children

Significant differences were observed in parents’ ratings of the QOL of pediatric liver transplant recipients and other children in the community. The QOL of children who had received a liver transplant was rated as significantly lower than the QOL of non-transplant children. This finding is congruent with conclusions drawn from several previous studies (Avitzur, et al., 2004; Bucuvalas, et al., 2003; Midgley, et al., 2000; Zamberlan, 1992), and the QOL scores obtained for both transplant and non-transplant samples are comparable with previous research (Weissberg-Benchell, et al., 2010).
While the results of the current study support some previous research, findings differ from the only other investigation of the QOL of Australian pediatric liver transplant recipients (Chin, et al., 1991). Chin and colleagues (1991) reported comparable QOL of transplant recipients to other children in the community. A possible explanation for this incongruence in findings is the operationalisation and measurement of QOL in the earlier study; VABS is designed to measure a person’s adaptive level of functioning and assesses communication, daily living, and socialisation. Psychological functioning, considered an integral element of QOL, is not measured with the VABS. It has not been validated as an adequate measure of QOL and does not usually feature in studies of QOL. Current results are also not reflective of Taylor and colleagues’ (2005) conclusion of no significant differences in the QOL experienced by children who have received liver transplants and other children in the community.

The significant difference in QOL experiences of transplant and non-transplant children identified in the current study may be a reflection of the ongoing health difficulties and lifestyle restrictions faced by children who have received liver transplants. Although a life-saving procedure, it must be remembered that pediatric transplant recipients were previously seriously unwell with ESLD to the point at which they would not have survived without a transplant. Furthermore, although transplantation has benefited from major medical advances, it remains major surgery after which significant recovery time is required. Similar to other transplant recipients, it is likely that the pediatric liver transplant recipients in the current study experience ongoing health difficulties and must adhere to a daily medication regimen. As such, the current findings also support the conceptualisation of QOL as a subjective construct that is independent of physical health.
As parent-proxy was used to assess children’s QOL in the current study, results may be reflective not only of children’s QOL, but also parental experiences. Parents accompany their children through ESLD and the traumatic experience of transplantation, and the impact of such stress on parents is well documented (Rodrigue, et al., 1997). One parent’s comment that “the day of transplant and following months are still very raw in our minds” illustrates that even if a child is too young to completely remember their illness and subsequent transplant, parents are unlikely to forget the extent of their child’s illness and the trauma of the transplantation process. This in itself has implications for the study of QOL, and suggests that the QOL of families should also be investigated. Further consideration of the limitations around the use of parent-proxy reports is detailed later in this chapter.

Results of the current study also support the notion that although the QOL of pediatric liver transplant recipients is not usually comparable to other children in the community, they are able to achieve good QOL outcomes (Alonso, et al., 2003; Midgley, et al., 2000). This point is highlighted by comparisons of transplant recipients’ QOL to that of children experiencing other chronic illnesses. The average score of parent-proxy reports of transplant children’s QOL in the current study (77.79) is similar or better than that of diabetes (76.56) (Varni et al., 2003), pediatric cancer (72.20) (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002), asthma (72.44) (Varni, Burwinkle, Rapoff, Kamps, & Olson, 2004), and arthritis (70.97) (Varni et al., 2002). This suggests that although transplant recipients’ QOL is unlikely to reach the level of other children in the community, it appears their enjoyment of life is comparable to children experiencing other health difficulties. Recent research has also
noted similarities between the QOL of children who have undergone liver transplantation, renal transplantation, and cancer treatment (Limbers et al., 2011).

Results of the current study suggest wide variation in the QOL experiences of individual transplant patients. The wide variety in QOL experiences of pediatric liver transplant patients, as indicated by the substantial standard deviation in scores, is consistent with previous research (Weissberg-Benchell, et al., 2010). This indicates that while some children’s QOL is rated highly and may in fact reach a comparable level of non-transplant children, other children are experiencing a QOL below that of their transplant peers and far below that of other children in the community. As comparable wide variability of QOL was not observed in the non-transplant group of the current study, it may be speculated that such vast differences in the QOL of transplant recipients is related to transplant-specific factors. Further research is required to identify the relationship between transplant-specific factors and the QOL of young transplant patients.

**Transplant-Specific Quality of Life**

Few studies have investigated specific transplant-specific factors, such as medication and pain, in relation to the QOL of transplant recipients. The results of the current study demonstrate the long-term implications of transplantation on the daily lives of young transplant recipients, and suggests that consideration of such factors leads to a more comprehensive understanding of the life experiences of young people following organ transplantation. Overall, parents of pediatric transplant patients in the current study reported children to experience good QOL related to medication adherence and side effects, physical appearance, and physical discomfort. Less optimal QOL was reported in relation to anxiety about ongoing treatment and peer relationships.
Medication. Medication is a routine aspect of daily life for transplant patients. While medication doses are reduced with improved health and time elapsed post-transplant, the majority of liver transplant recipients must remain on medication for the remainder of their lives (Burra & De Bona, 2007). Possible side effects of immunosuppressive medications prescribed after liver transplantation include changes in mood, hair loss or hair growth, bone and muscle weakness, stunted growth, nausea, vomiting, and diarrhea. Despite life-long medication that may have numerous side effects, the young people in the current study were reported to experience the best QOL in relation to medication side effects, implying that they are not concerned by adverse consequences of medication. This is consistent with previous research in which parents of liver transplant recipients identified their children as experiencing minimal problems related to medication side effects (Weissberg-Benchell, et al., 2010).

Parents of transplant recipients also reported good QOL related to adhering to a medication regimen. This is consistent with previous research (Weissberg-Benchell, et al., 2010), and also congruent with findings of qualitative research conducted with child and adolescent transplant recipients. One child in a previous study likened the daily routine of taking medication as ‘just like brushing your teeth’ (R. M. Taylor, et al., 2010). It may be that despite the annoyance of a daily medication regimen, the perceived burden is less than that of the types and amounts of medication required during ESLD and immediately post-transplantation. When considered in the context of the extensive surgical and medical histories and severe ESLD experiences endured by these children, the requirement of daily dosages of medication may be viewed as a relatively small encumbrance.
**Treatment anxiety.** Parents reported that ongoing anxiety about treatment impacted most upon pediatric patients’ QOL, indicating that children are most worried by ongoing visits to the doctor or hospital, injections and needles, and medical procedures. This may be because of the physical discomfort associated with procedure, or that continued treatment serves as a painful reminder of ESLD and the transplantation process.

Despite prevalent anxiety about treatment being clearly identified in the current study and previous quantitative research (Weissberg-Benchell, et al., 2010), this issue has not been widely investigated in other studies. Procedural pain was identified as salient to the QOL by several young transplant recipients in Wise’s (2002) study, with needles, blood drawing and insertion of nasogastric tubes labeled as frightening parts of the hospital experience. Information regarding children’s ongoing worries about treatment may inform decisions to make medical procedures brief and infrequent, and inform parents and children of the treatment rationale. The delivery format of this information is also known to effect children’s and families’ perceptions of medical interventions. Previous research has hypothesised that avoidance and anxiety around ongoing treatment among pediatric liver transplant recipients is symptomatic of post-traumatic stress disorder (PTSD) (Shemesh et al., 2000). While most children experience anxiety about medical procedures, special attention should be paid to children experiencing heightened levels of anxiety following transplantation, as this may be evident of greater psychological concerns. Other cognitive and behavioural interventions to help children cope with painful procedures may also be useful, together with education to inform parents of strategies to best prepare children for such procedures (McCarthy, Cool, Petersen, & Bruene, 1996).
**Peer relationships.** Peer relationships were identified as a prevalent concern in the lives of pediatric liver transplant recipients. Parents strongly endorsed questionnaire items related to others treating their child differently because of illness, others not understanding what they have been through, feeling left out, and having difficulty talking to others about their illness or transplant. The experiences of the children in the current study correspond to those reported in previous studies; liver transplant recipients often report difficulty socialising with other children, feelings of loneliness, and a desire to not be perceived as different from other children, especially upon return to school after a long absence (R. M. Taylor, et al., 2010; Wise, 2002; Zamberlan, 1992).

Results of the current study also provide tentative support to previous studies’ speculation of the relationship between young transplant recipients’ physical appearance and peer relationships (R. M. Taylor, et al., 2010; Wise, 2002). Correlation analyses in the current study indicated that children who experienced minimal concerns about physical appearance related to transplantation, such as scarring or being embarrassed by others seeing their body, were most likely to experience good QOL related to peer relationships.

**Transplant-specific factors and quality of life.** Correlational analyses identified significant associations between pediatric transplant recipients’ QOL and several transplant-related factors. Most saliently, children who had good peer relationships were more likely to achieve good QOL outcomes. This preliminary finding supports and extends upon previous research by identifying transplant-specific factors that are associated with pediatric recipients’ difficulties with peer relations (Alonso, et al., 2003; Tornqvist, et al., 1999). Furthermore, children who worried about transplant-related issues such as organ rejection and medication were least
likely to experience optimal QOL, suggesting the need for clear age-appropriate
communication with children about transplantation and their current health status.
Consistent with Fredericks and colleagues’ (2007) finding of medication non-
adherence being related to lower QOL, results of the current study also identified a
significant association between transplant recipients’ overall QOL and good
adherence to medication. Whilst causal relationships cannot be demonstrated in the
current study, these preliminary findings indicate potential areas of future research
that may ascertain the relative contribution of each of these transplant-related factors
to pediatric liver transplant recipients’ QOL. Focusing on QOL may be important for
increasing treatment adherence, and therefore physical health outcomes.

**Family Functioning**

The family functioning of pediatric transplant patients has received scant
attention in pediatric transplantation literature despite recognition of the important
role of parents and immediate family members in a child’s recovery following
transplantation (Fredericks, et al., 2007; Lurie, et al., 2000). The current study
identified substantial differences in the family functioning of transplant and non-
transplant families, with the families of pediatric liver transplant recipients making
significantly more adjustments to family routines to accommodate their children.

Results of the current study support Alonso and colleagues’ findings of
transplant families experiencing limited type and frequency of family activities
(2003). However, these findings are contrary to most previous investigations of the
family functioning of pediatric transplant patients, and refute the early claim by
Korsch and colleagues (1973) that family life returns to normal following pediatric
transplantation. Alonso and colleagues’ (2008) conclusion of no difference in the
family functioning of transplant and non-transplant families is not supported.
However, it should be noted that the difference in findings may be due to the distinct conceptualisations of family functioning between studies. Furthermore, while the current study did not compare the family functioning of families pre- and post-transplant, anecdotal evidence drawn from parents’ comments suggest the difficulties experienced by families with a child awaiting transplantation (Fredericks, et al., 2007; LoBiondo-Wood, et al., 2004; Stone, et al., 1997): “we dropped everything to care for her in the same way most liver families do”, “had we been responding back [pre-transplant] our responses would have been swayed towards the extreme end of the spectrum”, and “prior to the transplant it was a very different story and under the family accommodations questions almost all answers would have been at the other end of the scale.”

**Childcare.** Parents of pediatric liver transplant recipients reported most demand on childcare resources, citing increased need to monitor their child and increased need for transportation. The current study is the first to formally identify experiences with childcare as a significant difference in the functioning of transplant and non-transplant families. This finding emphasises the importance of promoting and supporting families post-transplantation. Other factors not explored in this study, such as family structure and resources (e.g., financial), as well as parents’ coping strategies, may shed further light on how best to support families with childcare difficulties in the post-transplantation period.

**Other areas of family functioning.** In addition to childcare, several other areas of family functioning were investigated in the current study. No significant differences were observed between transplant and non-transplant families in the areas of employment, services, domestic workload, assistance from others, child peer groups, marital roles, or parent information. However, it is noteworthy that parents of
liver transplant recipients reported making more accommodations in all areas except for parent information, indicating they received adequate information related to their child’s health and wellbeing and did not seek out further material. Further, given the current study’s small sample size and the likely lack of adequate statistical power to detect small differences, the trend of results indicates possible differences to the adjustments made by transplant and non-transplant families in the areas of domestic workload, assistance from others, and child peer groups. Potential changes made to parent relationships and marital roles following pediatric transplantation are aptly illustrated by a parent’s comment that her child’s ESLD diagnosis “was the trigger for marriage breakdown.” Two comments on the impact of children’s transplantation on employment appear to oppose Stone and colleagues’ finding that parents return to normal levels of employment following transplantation (Stone, et al., 1997): “I gave up work for two years after transplant and went through 5 [organ] rejections”, and “my wife can’t work (14 years) due to our son’s illness. I have to work two jobs – one full time, one part time.”

**Improvements in Quality of Life and Family Functioning Across Time**

The current study found that QOL improvements are not associated with time-elapsed post-transplantation. No significant differences were detected between the QOL of recipients transplanted 1-6 years ago and 7-12 years ago. However, current results show that QOL fluctuates over time following transplantation. This may reflect other factors not considered in the current study, including medical stability or pre-morbid levels of illness. It may be that QOL plateaus at a certain point in time, and lends support to previous findings of rapid QOL benefits being experienced in the short-term follow transplantation (Cole, et al., 2004). While it is widely accepted that QOL improves from pre- to post-transplant (R. Taylor, et al., 2005), these results are
somewhat contrary to Avitzur and colleagues’ finding of the excellent QOL of patients ten years after liver transplantation (Avitzur, et al., 2004).

As expected, the trend of results indicates that families make fewer adjustments to routines as time elapses after transplantation. However, the families of patients most years post-transplant actually report making more adjustments in comparison to those whose child has recently experienced transplantation. As our sample is small this may reflect an anomaly in the experiences of a small number of transplant families, or may be indicative of a family fatigued after many years of caring for a child with a chronic illness. Further research regarding this finding is warranted.

**Relationship Between Quality of Life and Family Functioning**

The current study is the first to directly investigate the relationship between QOL and family functioning of pediatric transplant recipients. Results showed an association between improved QOL and fewer adjustments to family routines, implying that improvement after transplantation may be associated with a child’s interaction with the home environment and other family members. This supports the hypothesis that adjustments made to family routines is associated with children’s wellbeing (Gallimore, et al., 1996; Weisner, et al., 2004), and extends established findings of the impact of family functioning on the QOL of children with disabilities to organ transplant patients.

The finding of a significant relationship between family functioning and QOL is congruent with two previous investigations of adolescents with cystic fibrosis and heart conditions (DeMaso, et al., 2004; Szyndler, et al., 2005), but show inconsistencies with previous studies that found no association between the QOL and family functioning of children with asthma and diabetes (Grey, et al., 1998; Sawyer, et al., 2001). However, it should be noted that such differences might be due to the
differences in measures. With preliminary findings of the current study suggesting that interventions aimed at providing stable family routines may improve QOL for children who have received liver transplants, further research is required to reach a better understanding of the inextricable link between QOL and family functioning. Such research may inform interventions or the provision of resources to families so that they can sustain healthy family routines with accommodating the needs of unwell children.

**Limitations of the Current Study and Directions for Future Research**

Several methodological issues limit the conclusions that may be drawn from this study. Firstly, this single centre study reflects the unique experiences of liver transplant patients from one location in Melbourne, Australia. Participants were at different stages of post-transplantation, and it was beyond the scope of the current study to control for ongoing medical complications that may impact QOL and family functioning. The relatively small sample size derived from the single centre restricted the ability to conduct mediation or predictive analyses. The correlational analysis used in this study does not allow conclusions to be made about the causal nature of the relationship between transplant-specific factors and pediatric transplant patients’ QOL. However, it informs several areas of research requiring further investigation with larger sample sizes, including young transplant patients’ experiences with peer relationships, anxiety about treatment, and medication adherence and side effects.

Parental assessment was used in this study; while parent insights into family functioning are appropriate, previous investigations have indicated difficulties with parent-proxy assessment of QOL. Parents of children with chronic illness have been found to over-estimate their child’s difficulties (Burra & De Bona, 2007). Tornqvist and colleagues (1999) reported that parental concerns and anxieties adversely
influenced ratings of their child’s competences, and transplant children have indeed
been found to rate their QOL as slightly higher than parents’ ratings (Weissberg-
Benchell, et al., 2010). While several studies point to good agreement between parent
and child reports of QOL and satisfactory conclusions being drawn from parent-proxy
reports, (Eiser & Morse, 2001; Herjanic, Herjanic, Brown, & Wheatt, 1975; Jokovic,
Locker, & Guyatt, 2004; Theunissen et al., 1998), future research should ideally
include the additional perspective of pediatric transplant recipients. Future research
should also consider the impact of demographic variables on QOL and family
functioning, as previous research has demonstrated differences in family functioning
due to characteristics such as socioeconomic status (Alonso, et al., 2008).

The rate of participation from transplant families in the current study was
adequate given the single-centre design, however, lack of information about the
transplant and non-transplant families who declined to participate limits the
generalisability of findings. Not having the time or capacity to complete and return
the questionnaire may be an indication of parental stress or inconsistent family
routines. Alternatively, parents who have concerns for their child’s QOL or the
wellbeing of their family may have been attracted to participate in the study, possibly
resulting in a biased sample. Investigation of the demographic characteristics of
families and medical history who chose not to participate may identify families
requiring assistance.

Further opportunities for research in this area of burgeoning interest are
plentiful. The brief qualitative responses from parents point to interesting hypotheses
regarding parents’ experiences of transplantation, the impact of pediatric
transplantation on marriage and employment, and, most pertinently, difficulties with
gaining appropriate childcare following transplantation. Furthermore, differences in
maternal and paternal perceptions of children’s QOL could be investigated. Given the wide variability of responses relating to pediatric patients’ QOL, further qualitative research would be well placed to investigate the individual experiences of transplant-related QOL, and quantitative analysis could be used to further explore factors such as medical stability that may contribute to recipients’ wellbeing.

The inclusion of a group of families whose children are currently on the waiting list to receive a liver transplant would provide additional information regarding the needs of families across the spectrum of pediatric ESLD and liver transplantation. Further investigations of family functioning could include explorations of siblings’ QOL, as illness and disability impacts upon the experiences of all family members (Davis & Gavidia-Payne, 2009).

**Concluding Comments**

The current study has demonstrated the importance of considering family functioning when evaluating the QOL of young recipients of liver transplantation. Results point to the ongoing challenges faced by pediatric liver transplant recipients and their families in the years after transplantation. The QOL of children who receive a liver transplant does not reach the same levels of other children, with anxiety about ongoing treatment a pertinent concern. This cross-sectional study has also shown the significant impact of the transplantation process on families; families make great adjustments to accommodate children following transplantation, and find childcare especially challenging. The preliminary findings of this study substantiate the need for further research to investigate the relationship between QOL and family functioning, and implore the need for greater psychosocial assessment and intervention aimed at increasing the functioning of pediatric transplant patients’ families.
Chapter 5

General Discussion

Quality of life is a heavily researched area within the field of organ transplantation, however a strong focus on the general measurement and quantification of the QOL of transplant patients has resulted in a lack of attention afforded to other aspects of QOL and transplantation. As such, theoretical models used to conceptualise QOL and the way in which health professionals perceptions and family functioning may impact the lives of transplant patients have received scant attention. The aim of this thesis, therefore, was to provide a comprehensive investigation of QOL in the field of organ transplantation. Taken together, the findings of the three studies provide an overview of the current standing of QOL research, and contribute unique knowledge to a growing body of literature dedicated to the psychosocial aspects of organ transplantation. The worth of broadening the scope of organ transplantation QOL research has been demonstrated by exploring QOL from several perspectives and methodological frameworks. Insights from transplant patients, health professionals, and the families of pediatric transplant patients have contributed to a holistic understanding of this area of research.

Summary of Findings

The investigation of the relationship between stress, coping, and QOL presented in Study 1 brought together several concepts that have previously been studied as separate constructs in the organ transplantation literature. This study built on past research that has consistently shown differences between the QOL of transplant candidates and recipients, and was the first to explore transplant patients’ QOL using the crisis theory model (Moos & Schaefer, 1986). In findings that supported previous research, the overall QOL of transplant candidates was found to be significantly lower
than that reported by transplant recipients and non-transplant individuals. However, differences among the QOL domains was not entirely commensurable with previous research, with the trend of results indicating that recipients experience better psychological QOL than non-transplant individuals. Overall, this study showed that the QOL of transplant patients can be explained in terminology consistent with crisis theory: patients who have survived the crisis of end-stage organ failure and the process of transplantation appear to have developed coping skills that enable them to adequately manage stressful life events following transplantation. While transplant-related stress was not found to impact upon transplant patients’ QOL, findings revealed that transplant patients contend with a variety of transplant-related issues, including financial stressors, problems with interpersonal relationships, and concerns about future health. Transplantation does not completely eliminate stress, nor is it a panacea for the QOL problems of all transplant patients. However, the findings of this study add to a convincing body of research supporting transplantation as a viable option that has the potential to not only extend the life expectancy of individuals with end-stage organ failure, but also to improve QOL.

Study 2 sought to further broaden the scope of QOL research in the field of organ transplantation by investigating QOL issues from the perspective of health professionals. Results of this exploratory study revealed inconsistencies between health professionals’ attitudes towards QOL and their use of QOL information. Health professionals’ largely positive regard for QOL issues was incongruent with behaviour related to assessment and information. Findings suggest that a number of factors may be important to health professionals’ use of QOL information in clinical practice, including lack of training with QOL issues, lack of familiarity with QOL measures, and difficulty understanding and applying published research findings. While further
research is needed to clarify and extend upon the preliminary findings of this study, the overall positive attitude of health professionals towards QOL seems to suggest that QOL is currently accepted as an important construct in organ transplantation research and practice.

Study 3 explored a novel aspect of QOL that has received scant attention in the organ transplantation literature. The QOL experiences of young transplant patients were explored through an investigation of the family functioning and wellbeing of pediatric liver transplant recipients. With the home environment posited as important to the medical and psychosocial wellbeing of young children following organ transplantation (Alonso, et al., 2008), this study sought to examine the QOL of pediatric transplant patients and the way in which family routines are adjusted in order to accommodate children following transplantation. The QOL of children with transplants was found to be significantly lower than that of their non-transplant peers, suggesting that ongoing QOL issues remain for young liver transplant recipients. Findings of an association between reduced adjustments to family routines and improved QOL demonstrate the need to consider the home environment and family routines in relation to pediatric transplant patients’ QOL.

**Theoretical Implications**

Despite decades of research focused on the QOL of transplant patients, Study 1 of this thesis was the first to use a theoretical framework to explore ubiquitous findings of low QOL among transplant candidates and comparable QOL between transplant recipients and non-transplant individuals. In addition to demonstrating that the QOL of transplant patients can be explained by crisis theory, the findings provide empirical support for the theoretical underpinnings of the construct of QOL and exemplify several of its theoretical aspects, including the subjective nature of QOL
and the independence of QOL domains (Orley & Kuyken, 1994). Furthermore, with
the current studies demonstrating the complex nature of QOL and the multitude of
factors that contribute to the life quality of transplant patients, there is scope for the
development of an overall theoretical model of transplant patients’ QOL.

Subjectivity is a central component to the construct of QOL, and the fact that
QOL is judged from an individual’s perspective has been used to explain the
wellbeing and happiness of individuals who may be perceived as less fortunate than
others and therefore may be expected to experience less optimal QOL (McMillen,
1999). The findings of Study 1 aptly demonstrate the highly subjective nature of
QOL: despite probable ongoing health problems and lifestyle restrictions, transplant
recipients report very good QOL. Similarly, parents of pediatric liver transplant
recipients in Study 3 reported their children enjoy good levels of QOL, despite the
serious medical implications of end-stage organ failure and undergoing the stressful
experiences associated with the transplantation experience.

Overall, the current research has shown the usefulness of applying a theoretical
framework to the investigation of the QOL of transplant patients. Furthermore,
findings lend support to the conceptualisation of QOL as a fluid and subjective
construct (Felce, 1997).

**Proposed theoretical model of transplant patients’ QOL.** On the basis of the
synthesis of findings in the current thesis, a theoretical model of transplant patients’
QOL is proposed. As shown in Figure 8, the proposed conceptual model posits the
important association of individual characteristics, factors related to the illness
experience, and the home environment to transplant patients’ QOL. The model
demonstrates the complexity of QOL, and acknowledges that while QOL is
subjective, there are many external factors that influence it. Congruent with crisis
theory’s supposition of the contribution of stress and coping style to QOL, individual characteristics are hypothesised to comprise of subjective and personal factors that influence individuals’ QOL by shaping the experience of being a transplant patient. Connected to this, illness experience refers to the individuals’ experience of end-stage organ failure, and subsequent transplant candidacy and transplant procedure. Interactions with health professionals and the health system are also acknowledged as important to QOL. The outside layer of the model details the way in which patients’ home environment, support systems, family composition, accommodations to family routine, and relationship with caregiver may contribute to QOL. The arrows spanning the individual characteristics, illness experience, and home environment sections of the model indicate the fluid nature of the sections and the interaction between the variables. While some of the factors featured in the model have benefitted from isolated instances of academic attention, such as coping and individual characteristics, other factors require more urgent attention, such as home environment and family composition.
Figure 8. Proposed theoretical model of transplant patients’ QOL.

Implications for Clinical Practice

Findings of the current studies have several implications for the clinical care of transplant patients. For the first time in this field of research, a theoretical model has been provided that may be used to guide health professionals when making decisions related to patients’ QOL issues. The investigation of transplant patients’ QOL through the crisis theory framework has highlighted the importance of considering the
relationship between stress, coping, and QOL, in addition to a series of factors that may influence QOL. This has implications for both assessment and intervention in the clinical care of organ transplant candidates and recipients.

**Assessment.** Despite an abundance of past organ transplantation research investigating QOL, Study 2 of this thesis was the first to consider this topical issue in relation to health professionals and the clinical care of transplant patients. Preliminary findings in this area of research show that QOL is held in high regard, however, health professionals working with transplant patients appear to be unsure of the role or utility of QOL measures. While it seems that health professionals are currently unwilling to alter current practices to include formal QOL assessment, the recognition among health professionals of the increasing importance of QOL in this field was demonstrated by acknowledgement of the need for QOL instruction to be incorporated into health professionals’ training.

Assessment of transplant patients and identification of those patients who may not be coping well with the transplantation process is a necessary precursor to any intervention. As the results from Study 2 suggest, awareness of QOL issues is an integral step in health professionals’ ability to identify and assist patients with concerns related to QOL. As Santana and colleagues (2010) demonstrated, assessment of QOL in clinical care can be completed without being burdensome in terms of time or training.

**Intervention.** More than a decade after its original publication, Engle’s (2001) statement regarding the total absence of empirical data to inform psychosocial interventions for organ transplant patients holds true. Health professionals treating transplant patients are left to consult empirical studies from other disciplines or rely on general clinical experience when designing and implementing interventions. While
few interventions have been detailed in the literature, a focus on QOL interventions has long been posited as the next logical stage of transplant research (Barr, et al., 2003; Burker, et al., 2005; L. Cohen, Littlefield, Kelly, Maurer, & Abbey, 1998; Engle, 2001; Golfieri, et al., 2007). Research conducted in other health areas suggests the potential positive impact of psychosocial interventions on QOL. Intervention research is well established within the oncology field, and interventions involving physical exercise, nutrition, and psychoeducation have been found to positively influence the QOL of oncology patients (Dow Meneses et al., 2007; Marin Caro, Laviano, & Pichard, 2007; Smith, 1996). Further, Callaghan and Li (2002) found that pre-surgical coping skills training led to better post-surgery health and QOL outcomes and lower levels of anxiety among women undergoing elective hysterectomy. Such findings suggest the usefulness of intervention research in the field of organ transplantation.

The increasing calls for intervention research in the field of organ transplantation are supported by the findings of a study conducted by Rudis, Rudis, Lupo, Safady, and Bonne (2000), the recommendations of which are not yet current practice. Rudis and colleagues (2000) designed personal intervention programs for transplant patients and their families based on evaluations of life history, mental health, compliance to medical regime, health behaviours, and family support systems. More than half of the transplant patients in the study required intervention during the candidacy period, including crisis intervention for acute mental health reactions, ongoing individual and family psychotherapy, and assistance with organising reliable social support systems. The number of patients requiring intervention rose to 73% following transplantation. While these findings appear to indicate a pressing need for
psychosocial interventions among transplant patients, the study did not extend to an evaluation of the efficacy of the interventions.

There are several inherent challenges associated with the design and implementation of interventions aimed at improving the QOL of transplants patients. First, many transplant candidates are simply too unwell to actively participate in any form of individual or group intervention. The locations of transplant centres or hospitals with transplant facilities impacts the feasibility of providing ongoing support for transplant patients, as patients often travel long distances to attend appointments. Second, infrequent contact between health professionals and transplant patients in the months and years following transplantation may impact on the frequency of psychosocial appointments. Resource shortages, staffing demands, and funding restrictions also limit the availability of psychosocial support programs (Dew, Goycoolea, et al., 2004). For these reasons, the limited studies that have evaluated interventions designed to improve transplant patients’ QOL have not included face-to-face contact. An internet-based intervention was found to be effective in reducing anxiety and hostility among heart transplant recipients, with greater mental health and QOL benefits observed in patients who were more frequent users of a website featuring discussion boards, psychoeducation material, and online post-transplant skills workshops (Dew, Goycoolea, et al., 2004). Further, Napolitano and colleagues (2002) found that a telephone-based intervention consisting of emotional support and cognitive behavioural techniques was effective in improving lung transplant candidates’ general wellbeing and overall QOL.

While interventions were not detailed in this thesis, the theoretical and empirical findings arising from it provide the basis for the development and evaluation of interventions designed to assist transplant patients to achieve optimal QOL. The
finding in Study 1 that avoidant coping is associated with lower QOL suggests that interventions should focus on reducing avoidant coping rather than increasing active or problem-based coping skills. Lastly, the results of Study 3 suggest an association between pediatric transplant recipients’ QOL and the amount of adjustments made to family routine; with this in mind, assisting families with routine tasks such as the organisation of childcare or respite may contribute to a better QOL for young transplant patients and their families.

Few interventions for transplant patients have thus far been evaluated, despite ongoing findings of psychosocial difficulties among transplant patients. One such aspect that presents an immediate opportunity for investigation is the utility and effectiveness of support groups. While participation in support groups may not be possible for all patients due to geographical distance from the transplant centre or hospital, both informal and formal support groups are routinely offered to transplant candidates and recipients. Numerous online communities also provide virtual support through ‘chat rooms’ and discussion boards. While anecdotally cited as helpful for transplant patients, there has been no empirical validation of the potential of support groups to contribute to improved QOL (Engle, 2001). Other potential areas of research regarding interventions include the impact of physical activity on QOL, as transplant recipients who competed in the 1996 US Transplant Games reported higher QOL than other transplant patients (Painter, et al., 1997). Given the aforementioned difficulties with the implementation of interventions with this population, research in this field should seek to overcome distance problems by continuing to offer online interventions, or evaluate pre-existing interventions, such as support groups. In addition to having the potential to contribute to improving the QOL of transplant
patients, a move towards intervention research will also advance the current standing of transplantation research.

Methodological Issues and Limitations

The three studies contained within this thesis have advanced knowledge of QOL in the field of organ transplantation by exploring several different aspects of QOL via data collected from diverse groups of informants. However, there are several methodological issues and limitations that may affect the generalisability of the research findings.

Sample size and recruitment issues impacted upon the selection of statistical analysis techniques employed throughout this thesis. While the overall number of participants recruited for Study 1 was adequate, unequal participant numbers in the groups of transplant candidates and transplant recipients limited the ability to use the framework of crisis theory to explore potential differences in the contribution of stress and coping to the QOL of these two groups. Recruiting candidates to research is an ongoing problem affecting transplant research; smaller numbers of candidates in comparison to transplant recipients, together with high rates of ill health and mortality, hamper potential participation from people awaiting organ transplantation. Relatively small sample sizes in the other two studies could be counteracted in future investigations by designing multi-site research involving a number of hospitals or transplant centres. Furthermore, while the exploratory data analysis techniques used in Study 2 and Study 3 inform many areas of potential future research, the use of predictive statistical models in future research may lead to more definitive results and clearer conclusions.

The current research largely reflects the unique experiences of Australian transplant patients, health professionals, and families of pediatric liver transplant
recipients. Further research is required to determine the similarities and differences between the experiences of this group in comparison to individuals residing in other countries. Future research could also consider the different QOL experiences between countries with low posthumous donor rates, such as Australia, and those with high donor rates where the waiting time to receive an organ transplantation is substantially shorter.

The possible impact of response bias on the results of the three studies should also be considered. As participation in all of the studies was voluntary and anonymous, individuals with a special interest in QOL or concerns regarding their own QOL or that of their child may have been attracted to participate. This is also a pertinent concern regarding Study 2, as health professionals with an interest in QOL issues may have been more inclined to participate in the study. The characteristics of individuals who declined to participate in the studies was not analysed, and therefore conclusions cannot be drawn regarding differences between respondents and non-respondents. As such, potential differences between respondents and non-respondents should be considered in further research.

Other limitations associated with participant selection and statistical analyses include not distinguishing between transplant recipients on the basis of cadaveric or living donation. Further, due to limited sample size, transplant patients in Study 1 were not separated according to organ type. As these factors have been shown to potentially impact upon QOL, the variables of organ type and form of donation should be included in further research (Cotler, et al., 2003; Dew, et al., 1997; Pinson, et al., 2000).

In terms of research design, investigations of the QOL of transplant patients should ideally be longitudinal. Studies in which individuals are followed through the
process of candidacy, transplantation and recovery are preferable. However, it is especially difficult to conduct longitudinal research with transplant patients, as the transplantation process is highly unpredictable and waitlist times vary greatly. An alternative to longitudinal research is to incorporate retrospective information gathered from pre-transplantation evaluations and psychosocial screenings. However, this may also be difficult as records related to psychosocial information vary between and within hospitals and transplant teams (Olbrisch, et al., 2002).

The inclusion of qualitative data in Study 2 and Study 3 allowed insight into the experiences of transplant health professionals and transplant families that has not previously been featured in the organ transplantation literature. However, the small amount of qualitative information collected in the studies limited the use of traditional qualitative research interpretive techniques, such as coding. Conducting face-to-face interviews or collecting data from focus groups in future studies may result in greater use of qualitative data.

Quantitative measures employed across the three studies generally showed good psychometric properties. Two measures, the MD-QOL (Bezjak, et al., 2001) and the FAQ (Gavidia-Payne & Tainsh, 2007), were successfully adapted for use in transplantation research. Further refinement of these measures and ongoing validation studies may also demonstrate their suitability for further use in transplantation research. In particular, the FAQ could be used in further research to assess the family functioning of other chronically ill children, including pediatric transplant candidates. Providing reliable and valid tools with which to investigate QOL issues is likely to lead to a broader scope of transplantation research, therefore enabling a deeper consideration of the wide range of QOL issues in this field.
Directions for Future Research

Several directions for future research have been identified throughout the current thesis. The proliferation of transplantation research presents a number of pertinent investigative opportunities related to QOL. The three studies detailed in this thesis have the potential to be developed into larger, stand-alone studies, and replicating results with a larger sample would provide greater generalisability of findings. Future research needs to be theoretically driven and comprehensive, and should also consider the emerging area of limb and facial transplantation.

Organ donation rates. Any investigation of the QOL of organ transplant patients would be incomplete without consideration of organ donation rates. While this area has received substantial academic attention and Australian rates of posthumous donation have recently increased, there remains much scope for research into raising organ donation rates (Excell, et al., 2011; Hyde & White, 2007). The QOL benefits of organ transplantation have been established over decades of research, with transplant recipients consistently found to experience QOL advantages over transplant candidates (Burra & De Bona, 2007). The results of Study 1 extended upon this well established finding by demonstrating that transplant recipients report similar QOL experiences to the non-transplant population. With this in mind, it may be argued that the most efficient and effective way of optimising the QOL of individuals with end-stage organ failure is to focus on increasing posthumous organ donor rates. Similarly, recent advances in organ transplant surgery have seen a sharp rise in the number of living donors. Living donation is now encouraged in a wide variety of cases in pediatric transplantation, and adult-to-adult liver and kidney transplantation is also becoming increasingly frequent (Levine, 2004; Schiano, et al., 2001). In addition to saving the lives of many individuals with end-stage organ
failure, increased posthumous donor rates may facilitate QOL improvements. 

Previous research has demonstrated the association between increased time on waitlist and low QOL, and the psychological impact stemming from the uncertainty of not receiving an organ is also well documented (Diaz-Dominguez, et al., 2006; Zipfel, et al., 1998). Further research is required to establish the best possible pathways to increase posthumous and living donation rates.

**Theoretical investigations.** Study 1 demonstrated the efficacy of using a theoretical framework to explore the QOL experiences of organ transplant patients. Together with the proposed theoretical model of transplant patients’ QOL detailed in Figure 8, there are several other theories that could be used to explore the QOL of transplant patients. Ventegodt, Merrick, and Andersen (2003) developed a theory of QOL based on Maslow’s hierarchy of needs, with the integrative QOL theory exploring individuals’ attainment of higher order wellbeing. The inclusion of an existential component in Ventegodt and colleagues’ (2003) theory makes it a viable framework through which to explore the QOL of individuals who have experienced a life-threatening illness, such as end-stage organ failure. Jowsey and colleagues’ (2012) investigation of heart transplant recipients’ psychological QOL based on Seligman’s theory of attributional style could also be extended to explore other domains of QOL among transplant patients across different organ types. Other theoretical frameworks used in oncology research proffer explanatory models for the QOL of ill individuals. For example, the theory of uncertainty in illness posits the contribution of uncertainty to skill development and life quality, while other theories pose a link between meaning-making processes and QOL, and the role of expected and actual outcomes in the QOL of medical patients (King, 2012).
Developing an organ transplantation research agenda. Organ transplantation is the beneficiary of a vast amount of academic attention, however, much of the work is conducted in isolation and the field lacks collaboration between individual researchers and research centres across the various disciplines that investigate the QOL of transplant patients.

Ricordi (2011) advocates the need for greater collaborative research efforts in order to meet shared objectives in an efficient and effective manner. A thorough review of recent research may be an ideal starting point to inform the most suitable direction of future investigations, as a vast amount of QOL research has been conducted in the area of organ transplantation since Dew and colleagues’ (1997) comprehensive meta-analysis. Such a review could also investigate the impact of recent medical advances on QOL, as current transplant patients experience better health outcomes than those transplanted in previous decades (Simpson, 2012).

The extensive corroboration and replication of established QOL findings in the transplantation literature has long been criticised, with the repetitive exploration of the QOL differences between candidates and recipients purported as detrimental to the introduction of new investigative areas (Dew, et al., 1997). As detailed previously, many researchers have called for future research to focus on interventions aimed at increasing transplant patients’ QOL. With results of Study 2 showing high levels of readership of journal articles among those health professionals working in the field of organ transplantation, it is pertinent to ensure future published QOL research reflects current information rather than continuously confirming established findings.

Congruent with the findings detailed in Study 1, there is general consensus within the literature that transplantation leads to significant QOL improvements, with differences readily observed between the QOL experiences of transplant candidates
and their recipient counterparts (Burra & De Bona, 2007). However, individual QOL differences remain, and most studies report that not all transplant recipients enjoy QOL improvements (Bravata, et al., 1999; Falger, Landolt, et al., 2008; Myaskovsky et al., 2006). Future research could employ quantitative and qualitative methods to investigate the experiences of these clinically distinct individuals, with results likely to be useful in informing the design and implementation of interventions specifically aimed at improving the QOL of this subset of transplant recipients.

Similarly, recent research has emphasised the need to ensure future transplant research is inclusive and representative of all transplant patients. Schold and colleagues’ (2011) evaluation of a US-based registry of transplant recipients from which research participants are recruited revealed significant differences between recipients who participated in research and those who did not. Factors associated with recipient participation include educational status, race and ethnicity, gender, age, income, distance to transplant centre or hospital, and the size of the hospital or transplant centre at which transplantation surgery was performed. The study concluded that transplant recipients who participate in research experience superior transplant outcomes, which may suggest that benefit is derived from participation in research itself. The findings of systematic differences between participants and non-participants extols the need to ensure research participants are representative of the wider transplant population, thus ensuring the external validity and generalisability of study findings.

**Composite Tissue Allotransplantation.** Composite Tissue Allotransplantation (CTA) is an important area of emerging research. Also known as reconstructive surgery, CTA involves the transplantation of any combination of vascularised skin, subcutaneous tissue, blood vessels, nerves, muscle, and bone. Encompassing facial
and limb transplantation, CTA has been heralded as the next major area of transplantation in terms of clinical practice and academic investigation (Edwards & Mathes, 2011). The first successful hand transplantation was performed in France in November 2005, and has since been followed by several facial transplantations in Europe and the US. While difficulties associated with the medical and surgical aspects of solid organ transplantation have largely been resolved, CTA techniques are in the early stages of development and the surgery is still considered to be experimental. Reminiscent of the early stages of solid organ transplantation, the major challenge currently impeding the progress of CTA is the need for new immunosuppressive medication, as the rejection episodes experienced by facial and limb transplant recipients differ substantially from those of organ transplant recipients (Edwards & Mathes, 2011). Other challenges include donor availability, financial viability, and the development of ethical guidelines regarding informed consent and candidate selection (Hautz et al., 2011).

Unlike solid organ transplantation, CTA is not a life-saving procedure. Facial and limb transplant candidates are not terminally ill, however, individuals in need of this extensive reconstructive surgery experience a number of other challenges. Many have experienced extensive trauma, burns, or facial tumours that have caused severe disfigurement. This may lead to a disrupted sense of identity, diminished self-esteem, and functional impairment. Patients with severe facial deformities are often reclusive and feel socially inhibited, leading to problems with social relationships and a lack of employment opportunities (Hautz, et al., 2011).

Given the relatively recent introduction of CTA procedures, the psychosocial experiences of CTA recipients have not yet been thoroughly researched. Edwards and Mathes (2011) state that facial and limb transplantation result in both functional and
psychosocial benefits, and other preliminary research has found that CTA improves the QOL of recipients by up to 70% (Hautz, et al., 2011). However, QOL research in this field is very much in its infancy. Similar to the proliferation of QOL research in the field of organ transplantation that began in the 1980s, it is likely that investigations of the QOL of CTA recipients will increase with continued refinement of CTA medical procedures and associated pharmacological advances. With a prospective increase in recipients over the coming decades, there is also scope for the development of a CTA-specific QOL measure, which could build upon existing measures used to assess the QOL of individuals with facial deformities (Cunningham, Garratt, & Hunt, 2000).

**Concluding Comments**

Intense interest in the QOL of organ transplant patients followed the resolution of surgical and medical problems that plagued the early era of transplantation research. A proliferation of psychosocial research in the field of organ transplantation heralded the QOL benefits of the life-saving procedure of transplantation. However, despite copious amounts of research in this field, several pertinent aspects of QOL have been largely overlooked. Therefore, the current thesis sought to advance the understanding of organ transplantation and QOL by extending the scope of traditional psychosocial research. Results of three studies provided a holistic view of the current standing of QOL research in this field through investigation of issues from the unique perspectives of transplant patients, health professionals, and families of pediatric transplant recipients. While this research supports the notion of QOL being a subjective construct that should be primarily assessed from the viewpoint of the transplant patient, the importance of considering the role of others in transplant practice and research has been demonstrated by findings related to health
professionals’ use of QOL information and the association between family routines and the QOL of pediatric liver recipients.

Overall, it can be concluded that QOL remains an interesting and worthwhile concept to consider in relation to organ transplantation. However, in order to further advance the understanding of the theoretical and practical aspects of QOL in this field, research must diversify its objectives and methodologies. Doing so will ensure that the primary aim of facilitating optimal QOL remains a priority in the treatment of all organ transplant patients.
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Appendix A
Questionnaire (Non-Transplant Population) – Study 1

**Demographic information**

Please indicate your response by circling or writing your answers:

1. Are you male or female?   Male   Female

2. What is your age (in years)?   ......................

3. What is your current marital status?  
   Married    Widowed    Never married
   Divorced   Separated   In a relationship

3. What is your country of residence?   ......................

4. If you are an Australian resident, please state your postcode

   ......................

5. Please circle your annual household income in your local currency

   less than 10,000
   10, 000 to 19, 999
   20, 000 to 29, 999
   30, 000 to 39, 999
   40, 000 to 49, 999
   50, 000 to 59, 999
   60, 000 to 69, 999
   70, 000 to 79, 999
   80, 000 to 89, 999
   90, 000 to 99, 999
   100, 000 to 150, 000
   150, 000 plus

6. I have never received an organ transplant, or been on the waiting list to receive an organ transplant

   True   *I have never received an organ transplant, or been on the waiting list to receive an organ transplant*

   False  *I have received an organ transplant, or been on the waiting list to receive a transplant*
STRESS IN YOUR LIFE

These questions ask about your feelings and thoughts during the last month.

In the past month how often have you

<table>
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<th></th>
<th>Never</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Fairly often</th>
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<tr>
<td>1.</td>
<td>Been upset because of something that happened unexpectedly?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>2.</td>
<td>Felt that you were unable to control the important things in your life?</td>
<td>1</td>
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<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3.</td>
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<td>4</td>
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</tr>
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<td>4.</td>
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COPING WITH STRESS

These items deal with the way you have been coping with the stress in your life. Please indicate how often you use each particular way of coping.

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3 = I do this a medium amount
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<th>A lot</th>
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<td>2</td>
<td>I concentrate my efforts on doing something about the situation I’m in</td>
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<tr>
<td>3</td>
<td>I say to myself “this is not real”</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>I use alcohol or other drugs to make myself feel better</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>I get emotional support from others</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
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<td>6</td>
<td>I give up trying to deal with it</td>
<td>1</td>
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<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>I take action to try to make the situation better</td>
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<td>4</td>
</tr>
<tr>
<td>8</td>
<td>I refuse to believe that it has happened</td>
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<td>4</td>
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<tr>
<td>9</td>
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</tr>
<tr>
<td>10</td>
<td>I get help and advice from other people</td>
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<td>2</td>
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<td>11</td>
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<td>4</td>
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<tr>
<td>12</td>
<td>I try to see things in a different light, to make it seem more positive</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>I criticize myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>I try to come up with a strategy about what to do</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>I get comfort and understanding from someone</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16</td>
<td>I give up the attempt to cope</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>I look for something good in what is happening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18</td>
<td>I make jokes about it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19</td>
<td>I do something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20</td>
<td>I accept the reality of the fact that it has happened</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21</td>
<td>I express my negative feelings</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22</td>
<td>I try to find comfort in my religion or spiritual beliefs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23</td>
<td>I try to get advice or help from other people about what to do</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
<td>A medium amount</td>
<td>A lot</td>
</tr>
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<td>---</td>
<td>-----------------------------------------------------------------</td>
<td>------------</td>
<td>--------------</td>
<td>-----------------</td>
<td>------</td>
</tr>
<tr>
<td>24.</td>
<td>I learn to live with it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25.</td>
<td>I think hard about what steps to take</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26.</td>
<td>I blame myself for things that happened</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27.</td>
<td>I pray or meditate</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28.</td>
<td>I make fun of the situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
LIFE SATISFACTION

These questions ask how you feel about your quality of life, health, and other areas of your life.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

<table>
<thead>
<tr>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you rate your quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. How satisfied are you with your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about how much you have experienced certain things in the last two weeks.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A medium amount</th>
<th>A lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. To what extent do you feel that physical pain prevents you from doing what you need to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. How much do you need any medical treatment to function in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. How much do you enjoy life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. To what extent do you feel your life to be meaningful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. How well are you able to concentrate?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. How safe do you feel in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. How healthy is your physical environment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Are you able to accept your bodily appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. How available to you is the information you need in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. To what extent do you have the opportunity for leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. How well are you able to get around physically?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The following questions ask you to indicate how good or satisfied you have felt about various aspects of your life over the **last two weeks**.

<table>
<thead>
<tr>
<th>Question</th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. How satisfied are you with your sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. How satisfied are you with your ability to perform your daily living activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. How satisfied are you with your capacity to work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. How satisfied are you with yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. How satisfied are you with your personal relationships?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. How satisfied are you with your sex life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. How satisfied are you with the support your get from your friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. How satisfied are you with the conditions of your living place?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. How satisfied are you with your access to health services?</td>
<td>1</td>
<td>2</td>
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Your participation is greatly appreciated. Thank you.
Appendix B
Questionnaire (Transplant Patients) – Study 1

Demographic information

Please indicate your response by circling or writing your answers

1. Are you male or female? Male Female

2. What is your age (in years)?

3. What is your current marital status?
   Married Widowed Never married
   Divorced Separated In a relationship

3. What is your country of residence?

4. If you are an Australian resident, please state your postcode

5. Please circle your annual household income (in your local currency)
   less than 10,000
   10,000 to 19,999
   20,000 to 29,999
   30,000 to 39,999
   40,000 to 49,999
   50,000 to 59,999
   60,000 to 69,999
   70,000 to 79,999
   80,000 to 89,999
   90,000 to 99,999
   100,000 to 150,000
   150,000 plus

5. Please select the statement which best describes you:
   (a) I am currently on the waiting list to receive an organ transplant
      How long (in months) have you been on the waiting list to receive a transplant?
      ........................................
   (b) I am the recipient of an organ transplant
      How long ago (in months) did you receive an organ transplant?
      ........................................

6. Lastly, which organ type are you awaiting or have previously received?
   Heart Lung
   Heart & Lung Pancreas
   Kidney Liver
   Other (please state) ........................
STRESS IN YOUR LIFE

These questions ask about your feelings and thoughts during the last month.

In the past month how often have you

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never</th>
<th>Almost</th>
<th>Sometimes</th>
<th>Fairly</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Been upset because of something that happened unexpectedly?</td>
<td>1</td>
<td>2</td>
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<tr>
<td>2.</td>
<td>Felt that you were unable to control the important things in your life?</td>
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<td>Felt that you could not cope with all the things that you had to do?</td>
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COPING WITH STRESS

These items deal with the way you have been coping with the stress in your life. Please indicate how often you use each particular way of coping.

1 = I don’t do this at all  
2 = I do this a little bit  
3 = I do this a medium amount  
4 = I do this a lot

<p>|   |                                                                                           | Not at all | A little bit | A medium amount | A lot |
|---|----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | I turn to work or other activities to take my mind off things                                    | 1         | 2            | 3               | 4     |
| 2 | I concentrate my efforts on doing something about the situation I’m in                           | 1         | 2            | 3               | 4     |
| 3 | I say to myself “this is not real”                                                               | 1         | 2            | 3               | 4     |
| 4 | I use alcohol or other drugs to make myself feel better                                          | 1         | 2            | 3               | 4     |
| 5 | I get emotional support from others                                                              | 1         | 2            | 3               | 4     |
| 6 | I give up trying to deal with it                                                                  | 1         | 2            | 3               | 4     |
| 7 | I take action to try to make the situation better                                                 | 1         | 2            | 3               | 4     |
| 8 | I refuse to believe that it has happened                                                          | 1         | 2            | 3               | 4     |
| 9 | I say things to let my unpleasant feelings escape                                                | 1         | 2            | 3               | 4     |
|10 | I get help and advice from other people                                                           | 1         | 2            | 3               | 4     |
|11 | I use alcohol or drugs to help me get through it                                                   | 1         | 2            | 3               | 4     |
|12 | I try to see things in a different light, to make it seem more positive                           | 1         | 2            | 3               | 4     |
|13 | I criticize myself                                                                               | 1         | 2            | 3               | 4     |
|14 | I try to come up with a strategy about what to do                                                  | 1         | 2            | 3               | 4     |
|15 | I get comfort and understanding from someone                                                       | 1         | 2            | 3               | 4     |
|16 | I give up the attempt to cope                                                                    | 1         | 2            | 3               | 4     |
|17 | I look for something good in what is happening                                                    | 1         | 2            | 3               | 4     |
|18 | I make jokes about it                                                                            | 1         | 2            | 3               | 4     |
|19 | I do something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping | 1         | 2            | 3               | 4     |
|20 | I accept the reality of the fact that has happened                                                | 1         | 2            | 3               | 4     |
|21 | I express my negative feelings                                                                  | 1         | 2            | 3               | 4     |
|22 | I try to find comfort in my religion or spiritual beliefs                                          | 1         | 2            | 3               | 4     |
|23 | I try to get advice or help from other people about what to do                                   | 1         | 2            | 3               | 4     |
|24 | I learn to live with it                                                                          | 1         | 2            | 3               | 4     |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>A medium amount</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>25.</td>
<td>I think hard about what steps to take</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26.</td>
<td>I blame myself for things that happened</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27.</td>
<td>I pray or meditate</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28.</td>
<td>I make fun of the situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
## TRANSPLANT RELATED STRESS

This scale asks you about some stressful events that you may have experienced as an organ transplant patient. These questions ask you to fill out two separate scales: please rate *how often* you have felt stressed about the event, and *how stressful* the event was.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Fairly often</th>
<th>Very often</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Been pressured or inconvenienced by dealings with medical insurance companies?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Worried about your body rejecting the organ transplant?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>Experienced negative side effects from your medication?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>Not had your medical questions answered adequately?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>Felt that you a burden to others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>Worried that you will not receive an organ transplant?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>Lacked energy to do everyday activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>Worried about gaining weight?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
9. Been under financial strain? | Never 1 | Almost never 2 | Sometimes 3 | Fairly often 4 | Very often 5 | Not at all 1 | A little 2 | Somewhat 3 | Very 4 | Extremely 5

10. Felt that you do not have enough support from your family and friends? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5

11. Been inconvenienced by traveling to check-ups and medical appointments? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5

12. Felt that your relationship with significant others in your life has changed? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5

13. Been limited by dietary restrictions? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5

14. Worried about contracting other illnesses? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5

15. Worried about how your health will be in the future? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5

16. Been pressured or inconvenienced by the need to comply with doctors’ orders? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5

17. Noticed changes in your appearance? | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5
**LIFE SATISFACTION**

These questions ask how you feel about your quality of life, health, and other areas of your life.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

<table>
<thead>
<tr>
<th>1.</th>
<th>How would you rate your quality of life?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>How satisfied are you with your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about how much you have experienced certain things in the **last two weeks**.

<table>
<thead>
<tr>
<th>3.</th>
<th>To what extent do you feel that physical pain prevents you from doing what you need to do?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td>How much do you need any medical treatment to function in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.</td>
<td>How much do you enjoy life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6.</td>
<td>To what extent do you feel your life to be meaningful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7.</td>
<td>How well are you able to concentrate?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>How safe do you feel in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9.</td>
<td>How healthy is your physical environment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.</td>
<td>Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11.</td>
<td>Are you able to accept your bodily appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12.</td>
<td>Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13.</td>
<td>How available to you is the information you need in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14.</td>
<td>To what extent do you have the opportunity for leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15.</td>
<td>How well are you able to get around physically?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The following questions ask you to indicate how good or satisfied you have felt about various aspects of your life over the **last two weeks**.

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.</td>
<td>How satisfied are you with your sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17.</td>
<td>How satisfied are you with your ability to perform your daily living activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18.</td>
<td>How satisfied are you with your capacity to work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19.</td>
<td>How satisfied are you with yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20.</td>
<td>How satisfied are you with your personal relationships?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21.</td>
<td>How satisfied are you with your sex life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22.</td>
<td>How satisfied are you with the support you get from your friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23.</td>
<td>How satisfied are you with the conditions of your living place?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24.</td>
<td>How satisfied are you with your access to health services?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Your participation is greatly appreciated. Thank you.
Appendix C
Plain Language Statement (Non-Transplant Population) – Study 1

Invitation to Participate in a Research Project
Project Information Statement

Project Title
Stress, coping, and quality of life.

Investigators
Bianca Villarosa (Psychology Masters degree student).
b.villarosa@student.rmit.edu.au
Dr Mandy Kienhuis (Project Supervisor: Lecturer, Psychology, RMIT
University). mandy.kienhuis@rmit.edu.au, 03 9925 3019

You are invited to participate in a research project being conducted by RMIT University.
This information sheet describes the project in ‘plain English’. Please read this sheet
carefully and be confident that you understand its contents before deciding whether to
participate. If you have any questions about the study, please contact one of the
investigators, listed above.

Who is involved in this research project? Why is it being conducted?
The current study is being undertaken by Bianca Villarosa as part of a Masters of Clinical
Psychology degree, under the supervision of Dr Mandy Kienhuis. This study has been
approved by the RMIT Human Research Ethics Committee

Why have you been approached?
We are seeking participants to complete a questionnaire about stress, coping, and
satisfaction in several areas of life.
To participate in this study, you must be aged 18 years or older. Participants must not
currently be on the transplant waiting list, previously been on the organ transplant waiting
list, or have received an organ transplant. If you have been a transplant candidate or
recipient, please contact the investigators to receive the relevant questionnaire.

What is the current study about?
The current study is investigating the way individuals cope with stress, and how stress
and coping may affect quality of life. Specifically, we are investigating how organ
transplant patients cope with the stress associated with being a transplant candidate or
recipients, and how stress and coping may affect patients’ quality of life.

If I agree to participate, what will I be required to do?
Participation is completely voluntary. You will be asked to provide general demographic
information, and complete a short questionnaire about the way you cope with stress, and
your satisfaction in several areas of your life. All responses are anonymous and kept
confidential.
The questionnaire should take approximately 15 minutes to complete. The questionnaire
is available online or as a hardcopy.

What are the risks or disadvantages associated with participation?
While unlikely, answering some questions may raise issues of concern for some
individuals. If you are unduly concerned about your responses, you should contact the
investigators, who will discuss your concerns confidentially and suggest appropriate follow-up, if necessary.

**What are the benefits associated with participation?**

While there is no direct benefit to participants, it is hoped the current study will provide important information about the relationship between stress, coping, and quality of life of transplant patients.

**What will happen with the information I provide?**

All your responses will be anonymous and will remain confidential. Data will be analysed by group only, and as such no identifiable information will be included. Research data will be held securely at RMIT for a period of 5 years before being destroyed. This study may be submitted for publication, but only group results will be reported and your anonymity is assured.

Because of the nature of this data collection, we are not obtaining written informed consent from you. Instead, your return of the questionnaire in the pre-paid envelope, or online submission for completion on the internet, is taken as your consent to participate in the study.

**Security of the website**

Users should be aware that the World Wide Web is an insecure public network that gives rise to the potential risk that a user’s transactions are being viewed, intercepted or modified by third parties or that data which the user downloads may contain computer viruses or other defects.

**Security of the data**

This project will use an external site to create, collect and analyse data collected in a survey format. The site we are using is surveymonkey.com. If you agree to participate in this survey, the responses you provide to the survey will be stored on a host server that is used by RMIT University. No personal information will be collected in the survey so none will be stored as data. Once we have completed our data collection and analysis, we will import the data we collect to the RMIT server where it will be stored securely for a period of five (5) years. The data on the RMIT University host server will then be deleted and expunged.

**What are my rights as a participant?**

Participation in this study is completely voluntary. You have the right to withdraw anytime before returning the questionnaire material.

**Whom should I contact if I have any questions?**

You may contact the investigators, Bianca Villarosa (b.villarosa@student.rmit.edu.au), or Dr Mandy Kienhuis (mandy.kienhuis@rmit.edu.au).

Thankyou for your interest in this study; your participation is greatly appreciated.

Yours sincerely,

……………………………   ……………………………

Bianca Villarosa    Dr Mandy Kienhuis
BA, GradDipPsych, PgDipPsych

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. Details of the complaints procedure are available at: [http://www.rmit.edu.au/research/hrec_complaints](http://www.rmit.edu.au/research/hrec_complaints)
Appendix D
Plain Language Statement (Transplant Patients) – Study 1

Introduction to Participate in a Research Project
Project Information Statement

Project Title
Stress, coping, and quality of life.

Investigators
Bianca Villarosa (Psychology Masters degree student)
b.villarosa@student.rmit.edu.au
Dr Mandy Kienhuis (Project Supervisor; Lecturer, Psychology, RMIT University),
mandy.kienhuis@rmit.edu.au, 9925 3019

You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in ‘plain English’. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the study, please contact one of the investigators, listed above.

Who is involved in this research project? Why is it being conducted?
The current study is being undertaken by Bianca Villarosa as part of a Masters of Clinical Psychology degree, under the supervision of Dr Mandy Kienhuis. This study has been approved by the RMIT Human Research Ethics Committee.

Why have you been approached?
We are seeking individuals who are currently waiting for an organ transplant, or have previously received an organ transplant. Participants must be aged 18 years or older.

What is the current study about?
The current study is investigating the way individuals cope with stress, and how stress and coping may affect quality of life. Specifically, we are investigating how transplant patients cope with the stress associated with being a transplant candidate or recipient, and how stress and coping may affect quality of life.

If I agree to participate, what will I be required to do?
Participation is completely voluntary. You will be asked to provide general demographic information, and complete a short questionnaire about the way you cope with stress, and your satisfaction in several areas of your life. All responses are anonymous and kept confidential.
The questionnaire should take approximately 15 minutes to complete, and is available online or as a hardcopy.

What are the risks or disadvantages associated with participation?
While unlikely, answering some questions may raise issues of concern for some individuals. In this case, you should contact the investigators, who will discuss your concerns confidentially and suggest appropriate follow-up, if necessary.
What are the benefits associated with participation?
While there is no direct benefit to participants, it is hoped the current study will provide
important information about the relationship between stress, coping, and quality of life of
organ transplant patients.

What will happen with the information I provide?
All your responses will be anonymous and will remain confidential. Data will be analysed
by group only, and as such no identifiable information will be included. Research data will
be held securely at RMIT for a period of 5 years before being destroyed. This study may
be submitted for publication, but only group results will be reported and your anonymity is
assured.
Because of the nature of this data collection, we are not obtaining written informed
consent from you. Instead, your return of the questionnaire in the pre-paid envelope, or
online submission for completion on the internet, is taken as your consent to participate in
the study.

Security of the website
Users should be aware that the World Wide Web is an insecure public network that gives
rise to the potential risk that a user’s transactions are being viewed, intercepted or
modified by third parties or that data which the user downloads may contain computer
viruses or other defects.

Security of the data
This project will use an external site to create, collect and analyse data collected in a
survey format. The site we are using is surveymonkey.com. If you agree to participate in
this survey, the responses you provide to the survey will be stored on a host server that is
used by RMIT University. No personal information will be collected in the survey so none
will be stored as data. Once we have completed our data collection and analysis, we will
import the data we collect to the RMIT server where it will be stored securely for a period
of five (5) years. The data on the RMIT University host server will then be deleted and
expunged.

What are my rights as a participant?
Participation in this study is completely voluntary. You have the right to withdraw anytime
before returning the questionnaire material.

Whom should I contact if I have any questions?
You may contact the investigators, Bianca Villarosa (b.villarosa@student.rmit.edu.au), or
Dr Mandy Kienhuis (mandy.kienhuis@rmit.edu.au).

Thankyou for your interest in this study; your participation is greatly appreciated.

Yours sincerely,

…………………………   ……………………………
Bianca Villarosa    Dr Mandy Kienhuis
BA, GradDipPsych, PgDipPsych

Any complaints about your participation in this project may be directed to the Executive Officer,
RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V,
Melbourne, 3001.
Details of the complaints procedure are available at:
http://www.rmit.edu.au/research/hrec_complaints
Appendix E
Plain Language Statement (Monash Medical Centre Patients) – Study 1

Participant Information and Consent Form
RMIT University & Department of Nephrology, Monash Medical Centre

Full Project Title:
“Stress, coping, and quality of life”
Principal Researcher: Dr. Mandy Kienhuis
Lecturer, RMIT University, Melbourne
Email: mandy.kienhuis@rmit.edu.au

Associate Researchers: Ms. Bianca Villarosa
Provisional Psychologist – Doctoral Candidate, RMIT
University, Melbourne
Email: b.villarosa@student.rmit.edu.au

Associate Professor John Kanellis
Director of Transplantation, Monash Medical Centre
Email: john.kanellis@med.monash.edu.au

1. Introduction
You are invited to take part in this research project being conducted by RMIT University. Your
contact details have been obtained from the Department of Nephrology, Monash Medical
Centre. This because we are seeking individuals who are currently waiting to receive an
organ transplant to complete a questionnaire. The research project aims to investigate the
stress, coping, and quality of life experienced by organ transplant patients.

This Participant Information and Consent Form tell you about the research project. It explains
what is involved to help you decide if you want to take part.

Please read this information carefully. Ask questions about anything that you don’t
understand or want to know more about. Before deciding whether or not to take part, you
might want to talk about it with a relative, friend, or your local health worker.

Participation in this research is voluntary. If you don’t wish to take part, you don’t have to.
If you decide you want to take part in the research project, you are asked to provide your
consent. By doing this you are telling us that you:
• Understand what you have read;
• Consent to take part in the research project;
• Consent to be involved in the procedures described; and
• Consent to the use of your personal and health information as described.

This information sheet is yours to keep.

2. What is the purpose of this research project?
The current study aims to investigate the type of stress experienced by people who are
waiting for an organ transplant, how they cope with this stress, and their overall quality of life.
Previous studies have shown that waiting for a transplant is a stressful experience, and it is
hoped that this research project will build upon previous research to provide
recommendations for assistance for organ transplant patients.
It is anticipated that approximately 100 organ transplant candidates will take part in the study.
Individuals who have already received an organ transplant will also be invited to participate in
the study, along with people who have never received a transplant. The responses from these
three groups of individuals will be compared.
The results of this research will be used by the researcher, Bianca Villarosa, for a research
thesis as partial fulfilment of the requirements of a Doctoral degree in Clinical Psychology.
3. **What does participation in this research project involve?**
Participation in this study is completely voluntary, and involves completing the questionnaire pack. This should take about 15 minutes. You will be asked to provide general demographic information, and complete a short questionnaire about the way you cope with stress, and your satisfaction in several areas of your life.
All responses are anonymous and kept confidential. Your personal records at Monash Medical Centre will not be accessed at anytime. This is a stand-alone questionnaire, and you will not receive any follow-up phone calls or further correspondence regarding this project. There is no financial reimbursement for participating in this project.

4. **What are the possible benefits?**
There are no direct benefits to participants who choose to complete and return the survey. However, it is hoped that the current study will provide valuable information that may be used to design support services for organ transplant patients in the future.

5. **What are the possible risks?**
While unlikely, answering some questions may raise issues of concern for some individuals. In this case, you should contact the investigator, who will discuss your concerns confidentially and suggest appropriate follow-up, if necessary.

6. **Do I have to take part in this research project?**
Participation in any research project is voluntary. If you do not wish to take part, you do not have to. Given the anonymous nature of responses, you will not be able to withdraw consent after you have submitted the survey. Your decision to take part or not will not affect your relationship with Monash Medical Centre.

7. **How will I be informed of the final results of this research project?**
The researcher will provide the Department of Nephrology at Monash Medical Centre with a summary of the research findings approximately six months after final data collection.

8. **What will happen to information about me?**
All your responses will be anonymous and will remain confidential. Data will be analysed by group only, and as such no identifiable information will be included. Research data will be held securely at RMIT for a period of 7 years before being destroyed. Only the researcher will have access to the data. This study may be submitted for publication, but only group results will be reported and your anonymity is assured.

9. **Can I access research information kept about me?**
You must be aware that the information collected about you will not be able to be identified, as we are not collecting your name or other personal details. Therefore, you will not be able to access the information you have provided after submitting the completed questionnaire.

10. **Is this research project approved?**
The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Southern Health, incorporating Monash Medical Centre. The project has also been approved by the Human Research Ethics Committee of RMIT University. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. **Consent**
I have read, or have had this document read to me in a language that I understand, and I understand the purposes, procedures and risks of this research project as described within it. I have had an opportunity to ask questions and I am satisfied with the answers I have received.
I freely agree to participate in this research project, as described. Because of the nature of this data collection, we are not obtaining written informed consent from you. Instead, your return of the questionnaire in the pre-paid envelope is taken as your consent to participate in the study.
12. **Who can I contact?**

The person you may need to contact will depend on the nature of your query. Therefore, please note the following:

**For further information:**
If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project (for example, feelings of distress), you can contact the principal or associate researcher on 9925 7603 or via email at mandy.kienhuis@rmit.edu.au or b.villarosa@student.rmit.edu.au

**For complaints:**
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ms. Malar Thiagarajan</td>
<td>Director, Research Services</td>
<td>03 9594 4611</td>
</tr>
</tbody>
</table>

The information and contact sheets are yours to keep
Appendix F
Questionnaire – Study 2

SECTION 1  Demographics

Please answer the following questions by circling or writing your response

1. Please indicate your gender
   
   Male  Female

2. What is your age (in years)?
   
   ........................................

3. In which area do you practice?
   
   Medicine  Nursing  Social Work  Mental Health
   Physiotherapy  Other (please state)  ........................................

4. Please indicate your area of expertise (please circle all that apply):
   
   (i) organ type:
   Cardiac  Renal  Lung
   Liver  Other (please state)  .........................
   (ii) clinical population:
   Paediatrics  Adults  Combined paediatrics/adults

5. In what year did you complete your professional training:
   
   Prior to 1980
   1980 – 1990
   1991 – 2000
   2000 onwards

6. In what setting do you practice? (please circle all that apply):
   
   Hospital
   Academic institute
   Other (please state)  ..............................

7. Main practice responsibilities (please circle all that apply):
   
   Patient care
   Administration
   Teaching
   Other (please state)  ..............................
SECTION 2  Quality of Life

1. Quality of life (QOL) may be defined in many different ways. How do you define quality of life?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

SECTION 3  Clinical Experience with Quality of Life Issues

These questions relate to your attitude toward QOL issues and the way in which you may use QOL information in clinical practice.

Please indicate your level of agreeability to the statement below by using the following scale:

<table>
<thead>
<tr>
<th>Attitude toward quality of life issues</th>
<th>Not applicable</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Resources currently allocated to QOL should be used for basic transplant research</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Using published QOL information is essential to good transplant patient care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. QOL is a subjective concept that cannot be quantified</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. New QOL instruments are simply variations of previously ineffective tools</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. Published QOL data are not useful for individual patient care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>6. The emphasis on QOL is a passing fad that will diminish over time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7. QOL should be a required outcome measure for all Randomised Control Trials (RCTs) in transplant research</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8. The role of the health professional as an independent decision maker is jeopardized by the emphasis on QOL</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9. The emphasis on QOL is warranted in view of the lack of success in improving survival of transplant patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. Adding QOL to RCTs will make transplant patients more willing to participate</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Adding QOL to RCTs in transplantation research will decrease health professional participation</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>12.</td>
<td>Most of my patients are willing to accept a poor QOL for even a small chance of receiving a transplant</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.</td>
<td>Discussing QOL makes patients feel that they themselves are cared about, not just their disease</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14.</td>
<td>My primary responsibility in treating transplant patients is to save lives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15.</td>
<td>Follow-up visits are primarily for monitoring the health of the patients, and not to assess QOL</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16.</td>
<td>Attention to QOL makes treatment decisions difficult</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17.</td>
<td>In my opinion, prolonging survival with poor QOL is still a success</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18.</td>
<td>The most important benefit of QOL is that one can 'really treat the whole patient'</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19.</td>
<td>When I initiate QOL discussions, my patients interpret this to mean that transplant is not possible</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20.</td>
<td>Having to consider QOL sometimes reduces the medical professional's ability to make optimal medical decisions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Clinical use of quality of life resources**

<p>| 21. | I generally encourage my patients to complete QOL questionnaires | 1 | 2 | 3 | 4 |
| 22. | The information that QOL research provides about the relative impact of treatment options determines my treatment recommendation | 1 | 2 | 3 | 4 |
| 23. | I rely on my clinical experience to assess QOL | 1 | 2 | 3 | 4 |
| 24. | I often read studies reporting QOL results | 1 | 2 | 3 | 4 |
| 25. | I use published QOL results to modify my practice patterns | 1 | 2 | 3 | 4 |
| 26. | I am more likely to use toxicity information than QOL information when making treatment decisions | 1 | 2 | 3 | 4 |
| 27. | I use formal QOL questionnaires in my practice | 1 | 2 | 3 | 4 |
| 28. | My decision to initiate QOL discussions does not depend on whether the circumstances are curative or palliative | 1 | 2 | 3 | 4 |
| 29. | When I have to choose between prolonging survival or improving QOL, I usually attempt to prolong survival | 1 | 2 | 3 | 4 |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>30.</td>
<td>When transplant is possible but unlikely, I intend to discuss QOL issues much less than when dealing with an incurable situation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31.</td>
<td>When a treatment offers a high chance of cure in conjunction with potential long-term survival, I downplay its negative impact on QOL</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32.</td>
<td>I do not discuss QOL issues with my patients unless they ask about it first</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33.</td>
<td>When I feel that QOL considerations are important in particular cases, I discuss QOL issues with patients even if they did not indicate an interest</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34.</td>
<td>I use QOL to justify not giving toxic treatments that are of questionable benefit</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**Willingness to use quality of life resources**

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>35.</td>
<td>Even if QOL instruments had established validity and reliability, I would be reluctant to extrapolate the results to my patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36.</td>
<td>Since quantifying QOL is problematic, I will not use QOL data</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37.</td>
<td>Even if I were given more resources, I would not collect QOL information</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>38.</td>
<td>If collecting QOL data were less demanding of my resources, I would be more willing to collect it from my patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>39.</td>
<td>I would not ask ill patients to complete QOL questionnaires</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>40.</td>
<td>If I were responsible for training health-care professionals, I would advocate the use of formal QOL measures</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>41.</td>
<td>Generally, I will spend my time on clinical care and leave QOL to others</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>42.</td>
<td>I do not plan to incorporate QOL data in my practice</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>43.</td>
<td>It is likely that I will increase my use of QOL in the care of future patients</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>44.</td>
<td>If QOL results were easier to understand, I would be more likely to use them</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>45.</td>
<td>Even if published QOL results are shown to be clinically relevant, I am not likely to use them</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>46.</td>
<td>The more physicians are aware of the complexities of analyzing QOL, the less likely they will be to use them</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>47.</td>
<td>I would only be willing to use formal QOL assessment if required to do so by my institution or regulatory body</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix G
Plain Language Statement – Study 2

Project Title
Transplant patients’ quality of life: Medical professionals’ attitudes and clinical experience with quality of life issues.

Investigators
Bianca Denny (Candidate – Doctor of Psychology)
  bianca.denny@rmit.edu.au 9925 7742
A/Prof Susana Gavidia-Payne (Project Supervisor: Lecturer, Psychology, RMIT University)
  susana.gavidia-payne@rmit.edu.au, 9925 7710
Dr Mandy Kienhuis (Project Supervisor: Lecturer, Psychology, RMIT University)
  mandy.kienhuis@rmit.edu.au, 9925 3019

You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in ‘plain English’. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the study, please contact one of the investigators, listed above.

Who is involved in this research project? Why is it being conducted?
The current study is being undertaken by Bianca Denny as part of a Doctor of Clinical Psychology degree, under the supervision of Associate Professor Susan Gavidia-Payne and Dr Mandy Kienhuis. This study has been approved by the RMIT Human Research Ethics Committee.

Why have you been approached?
We are seeking medical professionals who work with organ transplant patients to share their views regarding quality of life issues for transplant patients. Participants must be aged 18 years or older.

What is the current study about?
The current study is investigating medical professionals’ attitudes towards the quality of life issues of transplant patients. Further, we are interested in the way in which quality of life issues are considered in clinical practice.

If I agree to participate, what will I be required to do?
Participation is completely voluntary. You will be asked to provide general demographic information, and complete a short questionnaire about your attitudes toward quality of life issues, clinical experience with transplant patients and quality of life concerns, and your awareness and use of research related to the quality of life of transplant patients. All responses are anonymous and kept confidential. The questionnaire should take approximately 10 minutes to complete, and is available online or as a hardcopy.

What are the risks or disadvantages associated with participation?
While unlikely, answering some questions may raise issues of concern for some individuals, as it is necessary to reflect on your own clinical experience and contact with patients. In this case, you should contact the investigators, who will discuss your concerns confidentially and suggest appropriate follow-up, if necessary.
**What are the benefits associated with participation?**
While there is no direct benefit to participants, it is hoped the current study will provide important information about medical professionals’ experience with quality of life issues. Further, it is hoped that results of the study will inform the future direction of transplant research related to quality of life considerations.

**What will happen with the information I provide?**
All your responses will be anonymous and will remain confidential. Data will be analysed by group only, and as such no identifiable information will be included. Research data will be held securely at RMIT for a period of 5 years before being destroyed. This study may be submitted for publication, but only group results will be reported and your anonymity is assured.
Because of the nature of this data collection, we are not obtaining written informed consent from you. Instead, your return of the questionnaire in the pre-paid envelope, or online submission for completion on the internet, is taken as your consent to participate in the study.

**Security of the website**
Users should be aware that the World Wide Web is an insecure public network that gives rise to the potential risk that a user’s transactions are being viewed, intercepted or modified by third parties or that data which the user downloads may contain computer viruses or other defects.

**Security of the data**
This project will use an external site to create, collect and analyse data collected in a survey format. The site we are using is surveymonkey.com. If you agree to participate in this survey, the responses you provide to the survey will be stored on a host server that is used by RMIT University. No personal information will be collected in the survey so none will be stored as data. Once we have completed our data collection and analysis, we will import the data we collect to the RMIT server where it will be stored securely for a period of five (5) years. The data on the RMIT University host server will then be deleted and expunged.

**What are you my rights as a participant?**
Participation in this study is completely voluntary. You have the right to withdraw anytime before returning the questionnaire material.

**Whom should I contact if I have any questions?**
You may contact the investigators, Bianca Denny, Dr Mandy Kienhuis, or Susana Gavidia-Payne, via details listed at the top of this document.

Thankyou for your interest in this study; your participation is greatly appreciated.

Yours sincerely,

……………………...       …………………...             ……………………. ..
Bianca Denny              A/Prof Susana Gavidia-Payne             Dr. Mandy Kienhuis
Doctoral Candidate

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001.
Details of the complaints procedure are available at:  
Appendix H
Introductory Letter to Parents (Transplant Families) – Study 3

Dear Parent,

We are writing to tell you about an upcoming research project being conducted by The Royal Children’s Hospital (RCH) and RMIT University. The research aims to investigate the quality of life of children who have received liver transplants, and evaluate the impact of the transplantation process on family functioning.

All parents with a child currently aged between 5 and 16 years who have received a liver transplant are invited to participate in the study. Participation will involve completing one questionnaire. With your consent, we will also access your child’s medical record to gather information about your child’s illness, details of their transplant, and demographic information. All information will remain anonymous and confidential.

You do not have to take part in this project. Declining to participate will not affect your access to the best available treatment options and care at The Royal Children’s Hospital.

We will be approaching you to invite you to participate in this project in the coming weeks. A clinical nurse may approach you in person with further information about the study if your child has an upcoming appointment at RCH. Alternatively, we may contact you by mail. You may also contact us ahead of your appointment time should you wish to receive further information sooner.

If you do not wish to be contacted again by our research team or have any queries, please contact the Principal Investigator, Bianca Denny, on 0432 993 859 or bianca.denny@rmit.edu.au.

Yours sincerely

Bianca Denny
Provisional Psychologist
Principal Investigator
RMIT University

A/Prof Winita Hardikar
Children’s Doctor
Department of Hepatology
The Royal Children’s Hospital

Kathe Beyerle
Transplant Coordinator
Department of Hepatology
The Royal Children’s Hospital

If you have any concerns about the project, or the way it is being conducted, and would like to speak to someone independent of the project, please contact:
Head of Department, Ethics and Research Department, Human Research Ethics Committee, The Royal Children’s Hospital, Telephone: (03) 9345 5044

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HREC Project Number: 31067

Research Project Title: Quality of life and family functioning following pediatric liver transplantation.
PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
FOR QUESTIONNAIRE/INTERVIEW-BASED RESEARCH

HREC Project Number: 31067

Research Project Title: Quality of life and family functioning following pediatric liver transplantation.

Dear Parent/Caregiver,

You are invited to participate in a research project being conducted by the Royal Children's Hospital (RCH) Liver Transplant Team and RMIT University. The research aims to investigate the quality of life of children who have received liver transplants, and evaluate the impact of the transplantation process on family functioning.

The Principal Investigator of this project is Bianca Denny from RMIT University. This project is part of a degree of Doctor of Psychology. The other investigators of the project are Associate Professor Winita Hardikar, Head of Hepatology, and Kathe Beyerle, Liver Transplant Coordinator (RCH).

We are asking you to take part because you are the parent of a child who has received a liver transplant. If you choose to participate in the study, you will be asked to complete a questionnaire, which should take about ten minutes. The questions ask about your child’s experiences as a liver transplant patient, and the impact this may have had on your family. You will only be required to complete one questionnaire, and the investigators will not contact you again regarding the project. We will also access your child’s medical record to gather further information related to your child’s illness, details of their transplant, and demographic information. All this information will remain anonymous and confidential.

We do not expect there to be any direct benefit to you if you take part in this project. However, we hope that the information we get from this project may assist in helping us to improve the transplant process for other patients and their families in the future.

We do not expect there to be any risks. The only inconvenience is the time to complete the questionnaire. If you do experience feelings of distress as a result of participating in the study, please contact Dr Susana Gavidia-Payne on 9925 7710. Dr Gavidia-Payne is a psychologist who is able to provide support to participants who experience distress.

All the information you give us will stay private and will only be used for this research project. It will be stored without your name so it cannot be identified by anyone except the research team. You have the right to access, and ask correction of, your
information in accordance with the Freedom or Information Act 1982 (Vic). We will keep your information for 7 years or until your child is 25 years old and after this time, we will destroy it. The results of the project may be presented at conferences and published in professional journals. The results will not identify you or your family in anyway.

A summary of results will be posted to all research participants at the conclusion of the study. Results will be of the whole group of participants, and will not make reference to any individual respondent.

You do not have to take part in this project. If you do not take part, it will not affect your access to the best available treatment options and care from The Royal Children's Hospital. You can also choose to withdraw your consent after completing the questionnaire, after which time none of your information will be included in the results. If you decide to withdraw your consent, please contact a member of the research team.

We hope that you will take part. Please complete the attached consent form and questionnaire and return them to us via the enclosed reply paid envelope. One of our research team may follow-up with you via a telephone call after you receive the questionnaire.

If you have any questions, or would like further information about this project, please contact Kathe Beyerle on 9345 7998 or kathe.beyerle@rch.org.au.

Yours sincerely

A/Prof Winita Hardikar  
Children's Doctor  
Department of Hepatology  
The Royal Children's Hospital

Bianca Denny  
Provisional Psychologist  
Principal Investigator  
RMIT University

Kathe Beyerle  
Transplant Coordinator  
Department of Hepatology  
The Royal Children's Hospital

If you have any concerns about the project, or the way it is being conducted, and would like to speak to someone independent of the project, please contact:

Head of Department  
Ethics and Research Department  
Human Research Ethics Committee  
The Royal Children's Hospital  
Telephone: (03) 9345 5044
CONSENT FORM FOR PARTICIPANT TO GIVE INFORMED CONSENT TO TAKE PART IN A RESEARCH PROJECT

HREC Project Number: 31067

Research Project Title: Quality of life and family functioning following paediatric liver transplantation

I (Participant name) ____________________________ voluntarily consent to take part in the above research project.

I am the parent of [please write your child’s name] ____________________________

- I believe I understand the purpose, extent and possible effects of my involvement in this project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children’s Hospital Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I understand I will receive a copy of this Participant Information Statement and Consent Form.

Participant Signature ____________________________ Date _________

I have supplied an Information Statement and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible effects of their involvement in this project.

Researcher Signature ____________________________ Date _________

Note: All parties signing the Consent Form must date their own signature.
Appendix K
Questionnaire (Transplant Families) – Study 3

Please answer the following questions. Remember, you do not have to answer any question that you do not want to. Please answer all that you wish to without spending too much time on any one question.

**FAMILY ACCOMMODATIONS**

Family accommodations refer to the adjustments you and your family make for your child’s illness. Accommodations can range from major adjustments to family life, such as moving house, or day-to-day adjustments, such as having to provide increased supervision.

Firstly, please tell us your role in your family (for example, Mum or Dad):

…………………………………………

This questionnaire contains a list of statements about the accommodations you and your family may make due to your child’s illness. Please rate the following accommodation statements on a scale of 1 to 5:

1 = strongly disagree  2 = disagree  3= neutral  4 = agree  5 = strongly agree

<table>
<thead>
<tr>
<th>Work</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I need to look for jobs that offer flexibility, so that I can look after my child</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>2. I have to work from home to support my child’s needs</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>3. Both my partner and I work so that we can support the services and insurance my child requires</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>4. My partner and I have had to reduce our time spent at work to look after our child</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>5. My partner and/or myself have taken a less desired job due to our need for flexibility</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Services</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Our family had to move so that we were closer to support services for our child</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>7. Effort is required for us to access these services (eg. travel, babysitting for other siblings, cost, time, etc.)</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>8. We have chosen a more expensive service, even if inconvenient, to benefit our child</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Home and community</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. For the safety and wellbeing of our child, our family home had to be altered</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>10. Our family home was selected so that we were closer to the hospital</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>11. Our family has had to move house to accommodate our child’s needs</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>12. Around the home, our child requires constant care</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>
## Domestic workload

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Strongly disagree</th>
<th></th>
<th></th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. We have decided not to have any more children because looking after our child has created such a high workload</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Help had to be hired to help around the house due to our child’s needs</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Our other children have had to start helping around the house due to our child’s needs</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. My domestic workload is greatly increased, due to my child’s illness</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

## Child care tasks

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>17. My child requires constant monitoring</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18. The need for transportation has increased due to my child</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

## Assistance

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>19. We ask for assistance from our extended family (ie. grandparents, aunts, uncles)</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>20. We pay for our child to have respite care, so that my partner and I can spend some time alone</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

## Child peer groups

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>21. I have to supervise my child while they are playing with other children</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

## Marital roles

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>22. We often have conflicts and disruption to our marriage due to our child</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>23. As parents, we share and collaborate on decisions equally</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

## Parent information

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>24. There are lectures and courses about our child’s illness, which we can attend</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>25. We feel that there are professionals we can approach about our child’s illness</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>26. When we first learnt of our child’s illness, there was plenty of information (ie. books, research on internet) available to us</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>27. There are organised programs in the community for our child’s illness, where we can go for information</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
### QUALITY OF LIFE

Children who have had a transplant sometimes have special problems. On the following pages is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by circling:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>if it is never a problem</td>
<td>if it is almost never a problem</td>
<td>if it is sometimes a problem</td>
<td>if it is often a problem</td>
<td>if it is almost always a problem</td>
</tr>
</tbody>
</table>

There are no right or wrong answers.

In the past ONE month, how much of a problem has your child had with…

<table>
<thead>
<tr>
<th>About his/her medicines I</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medicines making him/her feel sick</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Medicines making him/her feel grumpy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Forgetting to take his/her medicine</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Not wanting to take his/her medicines</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Difficulty swallowing medicines</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Not liking the taste of his/her medicines</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Not liking having to take his/her medicines all the times</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Difficulty fitting medicines into his/her day</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Getting angry when he/she has to take his/her medications</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>About his/her medicines II</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medicines making his/her stomach bloat ed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Medicines making his/her face look puffy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Medicines making his/her teeth look different</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Medicines making him/her gain weight</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Medicines making him/her hairy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Medicines making his/her gums swollen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Medicines keeping him/her from growing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Medicines giving him/her acne</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Transplant and others</td>
<td>Never</td>
<td>Almost Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Almost Always</td>
</tr>
<tr>
<td>---------------------------------------</td>
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<td>-----------</td>
<td>-------</td>
<td>---------------</td>
</tr>
<tr>
<td>1. Other people treating him/her</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>differently because of his/her illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Feeling different than other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>his/her age because he/she has had</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. His/her parents not letting him/her</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>do what he/she wants to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>because of his/her transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Other people not understanding</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>what he/she has been through</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Feeling left out of things because</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>of his/her illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Difficulty talking to other people</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>about his/her illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. His/her parents nagging him/her to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>take his/her medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. His/her doctors nagging him/her to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>take his/her medications</td>
<td></td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pain and hurt</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Getting stomachaches</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Getting headaches</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Getting backaches</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worry</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Worrying about side effects from</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>his/her medicines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Worry about whether or not his/her</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>medicines are working</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Worrying that something is wrong</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>when he/she doesn’t feel well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Worrying that his/her doctor will</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>find something wrong with him/her</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Worrying about whether or not</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>his/her transplant is working</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Worrying that he/she will have to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>have another transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Worrying that he/she won’t be able</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>to do the things he/she used to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>because of the transplant</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
### Treatment anxiety

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Getting anxious about seeing the doctor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Getting anxious about going to the hospital</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>Getting anxious about having needle sticks (ie., injections, blood tests, IV's)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>Getting anxious about when he/she has to have medical treatments/procedures (ie., biopsy)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Perceived physical appearance

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Not liking other people to see his/her scars</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Worrying that his/her medicines will change the way he/she looks</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>Being embarrassed when other people see his/her body</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Communication

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Difficulty telling the doctors and nurses how he/she feels</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Difficulty asking the doctors and nurses questions</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>Difficulty explaining his/her transplant to other people</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>Difficulty understanding what the doctors and nurses are telling him/her</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
YOUR COMMENTS

We are interested in your experience of participating in this research project. If you would like to do so, please use the space below to share your thoughts or suggest improvements.

Alternatively, you may contact the Kathe Beyerle via email – kathe.beyerle@rch.org.au. Participants experiencing feelings of distress following completing this survey may contact Dr Susana Gavidia-Payne on 9925 7710.

Thank you for your time.
Your participation is greatly appreciated.
Appendix L
Results Letter to Parents – Study 3

HREC Project Number: 31067

Research Project Title: Quality of life and family functioning following paediatric liver transplantation.

Dear Parent/Caregiver

In 2011 we contacted you regarding a research project being conducted by the Royal Children’s Hospital (RCH) Liver Transplant Team and RMIT University. The research investigated the quality of life of children who have received a liver transplant, and evaluated the impact of the transplantation process on family routines.

We are pleased to announce that the research project is now finished. Thank you to all the parents and caregivers who contributed to the study. A total of 32 families participated.

We found that:

- Families of liver transplant recipients make more changes to their family routines to accommodate their children in comparison to other families in the community.
- Finding appropriate childcare was the most common concern for parents of liver transplant recipients.
- Adjustments to family routines decreased as years passed after transplantation.
- Families who reported making fewer adjustments to routines also reported experiencing a higher quality of life.

We hope to publish the results of this study in the near future. Any publication will include results of the whole group of participants, and will not make reference to individual respondents. If you would like to receive a copy of the publication, or have any other queries, please contact Kathe Beyerle on 9345 7998 or kathe.beyerle@rch.org.au.

A/Prof Winita Hardikar
Children’s Doctor
Department of Hepatology
The Royal Children’s Hospital

Bianca Denny
Provisional Psychologist
Principal Investigator
RMIT University

Kathe Beyerle
Transplant Coordinator
Department of Hepatology
The Royal Children’s Hospital
Appendix M
Plain Language Statement (Non-Transplant Families) – Study 3

INVITATION
TO
PARTICIPATE
IN
A
RESEARCH
PROJECT

PROJECT INFORMATION STATEMENT

Project Title:
Family Functioning and Children's Health Related Quality of Life in Liver Transplant and Healthy Families

Investigators:
• Miss Ancuta Cora (Bachelor of Applied Science (Psychology) (Honours), ancuta.cora@student.rmit.edu.au)
• Associate Professor Susana Gavidia-Payne (Research Supervisor: Associate Professor, Health Sciences, RMIT University, susana.gavidia-payne@rmit.edu.au, 9925-7710)

Dear parent or guardian,
You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in straightforward language, or ‘plain English’. Please read this sheet carefully and make sure that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators.

Who is involved in this research project? Why is it being conducted?
This research project is being conducted by Ancuta Cora and her supervisor Susana Gavidia-Payne, and is part of Ancuta Cora’s degree (Bachelor of Applied Science (Psychology) (Honours)) at RMIT University.
The RMIT Human Research Ethics Committee and the Department of Education Ethics Committee have approved this project.

Why have you been approached?
You have been invited to participate in this research project, as you are a parent or guardian of a child between 5 and 16 years. You have been selected randomly. We are hoping to recruit approximately 200 families with healthy children in this age bracket.

What is the project about? What are the questions being addressed?
Former research has shown that children who have had a liver transplantation tend to have poorer health related quality of life (physically, mentally, and socially) compared to healthy children. Also, research has investigated what types of accommodations families of children with transplants tend to make in order to increase family functioning. The aim of this research is to identify if family functioning and children’s health related quality of life is different between two groups of families; (1) families of children who have undergone a liver transplant; and (2) families of healthy children.
If I agree to participate, what will I be required to do?
If you agree to participate in this research, you will be required to complete a questionnaire booklet, which can be filled out at home and returned to the investigators in a replied paid envelope. The questionnaire booklet will ask a few general questions about your family and yourself. There will be only two questionnaires, both of which will require you to circle a number that represents how much you disagree or agree with a statement. For example, you will be required to show on a 5-point scale how true the following statement is “My child requires constant monitoring”. The questionnaire booklet will take approximately 15 minutes to complete. You are welcome to look at the questions on the questionnaire to decide if you want to participate. There will be no other inconvenient aspects to this research, other than taking the time to complete and post the questionnaire booklet.

What are the risks associated with participation?
Engaging in this research does not present any perceived risks outside normal day-to-day activities. However, if you are unduly concerned about any of the items, or if you find participation in the project distressing, you should contact Associate Professor Susana Gavidia-Payne as soon as convenient. Associate Professor Susana Gavidia-Payne will discuss your concerns with you confidentially and suggest appropriate follow up, if necessary.

What are the benefits associated with participation?
There are no direct benefits in participating in this study. However, the findings of this project will assist us in identifying if family functioning influences children’s health related quality of life, and whether family functioning and children’s health related quality of life is different between transplant families and healthy families. This research project could inform and improve health services and interventions for families whose children experience a liver transplant.

What will happen to the information I provide?
Participation in this research does not require identifiable information, and is therefore anonymous. All provided information will be treated confidentially with only the current investigators, and investigators of the liver transplant sample, having access to the information. Any information that you provide can be disclosed only if (1) it is to protect you, your child or others from harm, (2) a court order is produced, or (3) you provide the researcher with written permission. The group data will appear in a student report and perhaps a journal article at most. All research information will be locked in a filing cabinet at RMIT University for a period of five years before being destroyed.

What are my rights as a participant?
Participation in this research implies given consent and is completely voluntary. You have the right to withdraw your participation at any time without prejudice. You have the right to have any unprocessed data withdrawn and destroyed, provided it can be readily identified. You also have the right to have any questions answered at any time. Also, if participants would like a report about the outcomes of this project, they are welcome to contact any of the investigators.

Who should I contact if I have any questions?
If you have any questions about this project, please contact Associate Professor Susana Gavidia-Payne on susana.gavidia-payne@rmit.edu.au or 9925-7710.
What other issues should I be aware of before deciding whether to participate?
There are no other obvious ethical issues that need addressing. All we ask is that you please provide the most honest response you can and if you have any concerns please contact the supervisor. Otherwise we hope you have a great experience participating in this research project.

Yours sincerely,

________________________
Ancuta Cora
Bachelor of Applied Science (Psychology) (Honours)

________________________
Associate Professor Susana Gavidia-Payne
Bachelor of Psychology, Master of Science, Ph.D

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. Details of the complaints procedure are available on the 'Complaints with respect to participation in research at RMIT' page.
Appendix N
Questionnaire Pack (Non-Transplant Families) – Study 3

RESEARCH PROJECT

Family Functioning and Children’s Health Related Quality of Life

PARENT QUESTIONNAIRE BOOKLET

Code:
Thank you for your interest in this research project. This questionnaire booklet has questions about:

* You and your family  
* The family accommodations you make for your child  
* Your perceptions of your child’s health related quality of life

Your name will not be required and all information provided in this booklet will be kept confidential. There are no right or wrong answers, so please answer all the statements as quickly as possible. Also, please remember that this booklet is to be completed for one child only. If you have more than one child, please select the child between the ages of 5 and 16 years of age, or if you have more than one child in this age group either select a child at random or request additional booklets. If you have any questions about this booklet, please contact Ancuta Cora or Associate Professor Susana Gavidia-Payne.

**General Information About Myself and My Family**

Firstly, we would like to ask you a few questions about you and your family. We will use this information to generally describe the people who responded to our questionnaire. We will describe people in groups, never as individuals, so your answers will be kept confidential. Please tick the appropriate box or fill in one answer per question.

1. What is your relationship to the child participating in this study?
   - Father
   - Mother
   - Other (Please Specify) ..........................................

2. What is your highest level of education completed?
   - Less than Year 12
   - High school graduate, Year 12
   - TAFE graduate
   - Undergraduate qualifications
   - Postgraduate qualifications
   - Other (Please specify) ..........................................

3. What is your marital status?
   - Married
   - Defacto
   - Divorced
   - Widowed

4. What is your postcode? ...........................

5. What is your employment status?
   - Full time
   - Part time
   - Unemployed but looking
   - Unemployed
   - Retired
   - Stay at home parent or caregiver
   - Other (Please specify) ..........................................

6. What was your total household income from all sources for the past year? Be sure to include income from all sources (such as child support).
   - Less than $25,000
   - Between $25,001 and $45,000
   - Between $45,001 and $55,000
   - Between $55,001 and
$75,000 □ Greater than $75,001
7. What is the gender of your child?
□ Female □ Male
8. What is your child’s age in years and months? ...............................
9. How many siblings (brothers and sisters) does your child have?
□ One □ Two □ Three or more
10. Who is the primary caregiver for your child?
□ Yourself □ Your partner □ Both
□ Other (Please specify) ...........................................
11. What is the name of the school your child currently attends?
..................................................................................................................
12. What grade/year is he/she in? .............................................
13. If applicable, has your child experienced a serious illness or long-term hospitalisation?
□ No □ Yes (If yes, please specify) ..........................................................

My Child in My Family

In this next section of the booklet we would like you to think about your family accommodations. Family accommodations refer to the adjustments you and your family makes to cater for your child’s health and well-being. Accommodations can range from major adjustments to family life, such as moving house, or day-to-day adjustments, such as having to provide increased supervision.

The questions in this section contain a number of statements about your family’s accommodations. Please read each statement carefully and decide how well it describes your family. You should answer according to how you currently see your family. There are no right or wrong responses. Please rate the following accommodation statements on a scale of 1 to 5 by circling:

1 = strongly disagree,
2 = disagree,
3 = neutral,
4 = agree,
5 = strongly agree

<table>
<thead>
<tr>
<th>Work</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>I need to look for jobs that offer flexibility, so that I can look after my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I have to work from home to support my child’s needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>3</td>
<td>Both my partner and I work so that we can support the services and insurance my child requires</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>My partner and I have had to reduce our time spent at work to look after our child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>My partner and/or myself have taken a less desired job due to our need for flexibility</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Services/Programs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Our family had to move so that we were closer to support services/programs for our child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>Effort is required for us to access these services/programs (e.g. travel, babysitting for other siblings, cost, time, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>We have chosen a more expensive service/program, even if inconvenient, to benefit our child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Home and community</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>9</td>
<td>For the safety and wellbeing of our child, our family home had to be altered</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>Our family home was selected so that we were closer to a hospital</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>Our family has had to move house to accommodate our child’s needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>Around the home, our child requires constant care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Domestic workload</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>We have decided not to have any more children because looking after our child has created such a high workload</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>Help had to be hired to help around the house due to our child’s needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>Our other children have had to start helping around the house due to our child’s needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16</td>
<td>My domestic workload is greatly increased, due to my child’s health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Child care tasks</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>My child requires constant monitoring</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18</td>
<td>The need for transportation has increased due to my child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Assistance</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>We ask for assistance from our extended family (i.e. grandparents, aunts, uncles)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20</td>
<td>We pay for our child to have respite care, so that my partner and I can</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
### My Child’s Quality of Life

In this next section of the booklet we would like you to think about your child’s health related quality of life and answer a few statements. Please read each statement carefully and decide how well it might be a problem for your child. There are no right or wrong responses. Please tell us how much of a problem each one has been for your child during the past one month by circling:

0 = if it is never a problem,
1 = if it is almost never a problem,
2 = if it is sometimes a problem,
3 = if it is often a problem,
4 = if it is almost always a problem

|  | | | | | |
|---|---|---|---|---|
| **Child peer groups** | | | | |
| 21 | I have to supervise my child while they are playing with other children | 1 | 2 | 3 | 4 | 5 |
| **Marital roles** | | | | |
| 22 | We often have conflicts and disruption to our marriage due to our child | 1 | 2 | 3 | 4 | 5 |
| 23 | As parents, we share and collaborate on decisions equally | 1 | 2 | 3 | 4 | 5 |
| **Parent information** | | | | |
| 24 | There are lectures and courses about our child’s health, which we can attend | 1 | 2 | 3 | 4 | 5 |
| 25 | We feel that there are professionals we can approach about our child’s health | 1 | 2 | 3 | 4 | 5 |
| 26 | When we first learnt of our child’s health, there was plenty of information (i.e. books, research on internet) available to us | 1 | 2 | 3 | 4 | 5 |
| 27 | There are organised programs in the community for our child’s health, where we can go for information | 1 | 2 | 3 | 4 | 5 |
### Physical functioning (problems with...)

<p>| | | | | |</p>
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<tr>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Walking more than 100 meters</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>2</td>
<td>Running</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>3</td>
<td>Participating in sports activity or exercise</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>4</td>
<td>Lifting something heavy</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>5</td>
<td>Taking a bath or shower by him or herself</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>6</td>
<td>Doing chores around the house</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>7</td>
<td>Having aches or pains</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>8</td>
<td>Having a low energy level</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
</tbody>
</table>

### Emotional functioning (problems with...)

<p>| | | | | |</p>
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<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Feeling afraid or scared</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>10</td>
<td>Feeling sad</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>11</td>
<td>Feeling angry</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>12</td>
<td>Having trouble sleeping</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>13</td>
<td>Worrying about what will happen to him or her</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
</tbody>
</table>

### Social functioning (problems with...)

<p>| | | | | |</p>
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<tr>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Getting along with other children</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>15</td>
<td>Other kids not wanting to be his or her friend</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>16</td>
<td>Getting teased by other children</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>17</td>
<td>Not being able to do things that other children his or her age can do</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>18</td>
<td>Keeping up when playing with other children</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
</tbody>
</table>

### School functioning (problems with...)

<p>| | | | | |</p>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>Paying attention in class</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>20</td>
<td>Forgetting things</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>21</td>
<td>Keeping up with schoolwork</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>22</td>
<td>Missing school because of not feeling well</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>23</td>
<td>Missing school to go to the doctor or hospital</td>
<td>No</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
</tbody>
</table>

You have finished this booklet. Thank you for your time! Please return the completed booklet in the supplied envelope.

Thanks again!