Quality of Life of Adolescents Following Heart Transplantation

by

Samantha J. Anthony

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Institute of Medical Science
University of Toronto

© Copyright by Samantha J. Anthony (2010)
Quality of Life of Adolescents Following Heart Transplantation

Samantha J. Anthony

Doctor of Philosophy

Institute of Medical Science
University of Toronto

2010

Abstract

Despite the establishment of heart transplantation as a life-saving therapy for children and adolescents, little research has focused on the biopsychosocial impact of the transplant process. Few studies have captured the subjective experiences of young heart transplant recipients. This program of research examined how pediatric heart transplant recipients construct their worlds and the meanings they ascribe to their transplant experience. A grounded theory approach was implemented which guided data collection and analysis. A total of twenty-seven adolescents participated in semi-structured qualitative interviews. Findings illuminate pediatric heart transplantation to be a pervasive experience, with consequent impact on physical, psychological and social well-being. Participants described various biopsychosocial processes and experiences that occurred over the course of their transplant journey. Data analysis yielded themes of quality of life reflecting notions of temporality including: 1) the pre-transplant experience – *a struggle to survive*, 2) the transplant surgery and hospitalization – *a difficult transition* and 3) the post-transplant experience – *an awakening and transformation*. This research identifies that heart transplantation, which may contain elements of suffering and loss, may ultimately enhance young recipients’ overall quality of life. Results reveal the possibility that adolescent heart transplant recipients not only adapt to transplantation, but also potentially experience associated
growth-enhancing experiences. An emergent theoretical model is presented, with implications for practice and research.
Acknowledgments

It is my pleasure to thank those people who made this thesis possible.

First and foremost, I would like to thank all of the adolescent heart transplant recipients who participated in this program of research. I have been profoundly moved by, and am deeply grateful for, their kindness and generosity in sharing a piece of their lives with me and allowing me the opportunity to learn about their world.

I offer my sincerest gratitude to my supervisor, Dr. Lori West, who provided me with unwavering encouragement and support. She inspired and enriched my growth as a student, clinician and researcher. I am truly grateful to my excellent advisory committee, Dr. Cheryl Regehr and Dr. David Nicholas, for their supervision, guidance and support. Without the enthusiasm and persistence of these three wonderfully talented and generous individuals this dissertation would not have been possible.

I would like to express my gratitude to Dr. Beverley Antle. Her energy, enthusiasm and dedication motivated me throughout my doctoral program. She was an inspirational mentor and I treasure the moments we shared. Although she is no longer with us, she is forever remembered. I hope she shares in my joy and happiness from heaven.

I am indebted to many of my colleagues who supported and encouraged me, in particular those within the Transplant Centre and the Department of Social Work. Special thanks to Radha MacCulloch, Dr. Anne Dipchand and Dr. Brian McCrindle for their support and assistance.

Finally, my deepest gratitude goes to my wonderful family. The dedication, love and support I have received from my parents throughout my life have made all the difference. I thank my brother, Ryan, for his wit and brilliance. I’m truly grateful to my loving partner, Mike and our beautiful daughter, Harrison. Mike’s understanding and support have helped to sustain me through the PhD Program. Being a mother to Harrison is a treasured experience that I truly cherish. Harrison has given me so much joy and inspiration, and blessed my life in countless ways. Words cannot express my heartfelt appreciation and love towards my family. Thank-you for your encouragement and for always cheering me on.
# Table of Contents

Abstract

iv

Acknowledgements

v

Table of Contents

vii

List of Appendices

1

Chapter 1: Introduction

1.1 Introduction

1

1.2 Background and Rationale

2

1.3 Research Question and Objectives

5

1.4 Organization of Dissertation

6

Chapter 2: Heart Transplantation

2.1 The History of Heart Transplantation

7

2.2 Symbolism of the Heart as a Transplanted Organ

9

2.3 Pediatric Heart Transplantation

10

2.4 Quality of Life following Pediatric Heart Transplantation

14

Chapter 3: Theoretical Framework and Quality of Life

3.1 Guiding Frameworks

20

3.2 Ecological Perspective: ‘person-in-environment’

20

3.3 Quality of Life

26

3.4 Assumptions

40
Chapter 4: Methodology

4.1 Research Approach 42

4.2 Research Design 45

4.3 Quality Criteria 53

Chapter 5: Results 56

5.1 Participants 56

5.2 Findings 57

Chapter 6: Discussion and Conclusion 81

6.1 Discussion 82

6.2 A Transformative Process 89

6.3 Study Limitations 95

6.4 Implications for Clinical Practice and Future Research 96

6.5 Conclusion 100

References 102
List of Appendices

Appendix A: Research Consent / Assent Forms 118
Appendix B: Interview Guide 127
Appendix C: Information Letter 128
Chapter 1
Introduction

1.1 Introduction

“Where it is possible to manage but not cure a disease, we must determine how far treatment and disease compromise a child’s quality of life.”

(Eiser & Morse, 2001a, p.1)

Innovations in healthcare have changed the emphasis of pediatric medicine from the treatment of infectious diseases to the management of chronic health conditions (Eiser & Morse, 2001a, 2001b; Peterson, Schmidt, Power, Bullinger & DISABKIDS Group, 2005; Upton, Lawford & Eiser, 2008). Recent technologic, diagnostic and pharmacologic advances have resulted in dramatic improvements in survival rates for a wide range of previously life-threatening conditions. While the life expectancy of children with chronic illnesses has significantly increased, new innovative therapies and treatments appear to be increasingly aggressive and are associated with both acute and long-term morbidity (Upton et al., 2008). These aggressive, sometimes ‘heroic’, medical protocols have prompted many to question the relationship between quantity and quality of survival, particularly where cure is not seen to be an option. While survival statistics have long been perceived as appropriate end-points when considering the efficacy of medical treatment, it has recently been acknowledged that a more holistic approach to disease management is necessary (Eiser & Morse, 2001a, 2001b).

Since 1948, when the World Health Organization defined health as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease’, quality of
life issues have become steadily more important parameters in health care and practice (Burra & De Bona, 2007; Connolly, Rutkowski, Auslender & Artman, 2002; Eiser & Morse, 2001a, 2001b; Testa & Simonson, 1996). The measurement of quality of life encompasses several broad domains including physical well-being, functional status, and psychosocial functioning, all of which are influenced by an individual’s experiences, beliefs and expectations (Aaronson, 1988; Burra & De Bona, 2007; Testa & Simonson, 1996). The evaluation of adult quality of life is now well-established, and is utilized to assess outcomes, describe treatment impact, and examine patients’ experiences with medical care (Aaronson, 1988). Despite a growing recognition of the utility of these evaluations, interest in children’s quality of life has only recently gained momentum (Eiser & Morse, 2001a, 2001b; Testa & Simonson, 1996). Critical catalysts in promoting assessment of quality of life in children include: 1) the recognition that treatment modalities should not only increase life expectancy, but also improve quality of life, and 2) the philosophy of patient and family-centred care that incorporates patients/families’ values and preferences in treatment decisions and promotes enhancing patient capacity for self-management in health needs (Eiser & Morse, 2001a, 2001b). Quality of life is now emerging as an essential outcome and an integral component in pediatric practice, in particular in the field of transplantation (Eiser & Morse, 2001a, 2001b; Testa & Simonson, 1996).

1.2 Background and Rationale

Heart transplantation is an established therapeutic approach for children and adolescents with end-stage heart disease (Kirk et al., 2009). Since its infancy, the number of heart
transplants performed worldwide has exponentially grown and in total, approximately 8,058 pediatric heart transplants have been performed worldwide (Kirk et al., 2009). With significant advances in both the surgical and medical management of transplantation, the outcomes for pediatric heart transplant recipients have improved substantially, with five-year survival rates for recipients approaching 80% (Kirk et al., 2009).

Long-term survival for pediatric heart transplant recipients has been accompanied by a recognition that the requirements in post-transplantation care are both wide-ranging and demanding. Pediatric transplant recipients face life-long medical follow-up that includes regular clinic visits as well as frequent, often invasive medical tests and procedures, such as biopsies for rejection surveillance and coronary angiographies to detect transplant coronary artery disease. Immunosuppressive drug therapy with accompanying side-effects such as high blood pressure and kidney dysfunction, growth delay, infectious risks, possible malignancies as well as cosmetic effects, all impact the day to day life of the child (Suddaby, 1999).

Despite the growth of heart transplantation as a life-saving therapy in children and adolescents, little research has focused on the biopsychosocial impact of the transplant process. A review of the existing literature examining the biopsychosocial impact of pediatric heart transplantation yields mixed findings and outcomes. Some studies reflect that pediatric heart transplant recipients demonstrate improved psychological functioning post-transplant and exhibit adequate adjustment to the psychological stress of

However, studies also suggest that pediatric heart transplant recipients are at increased risk of impaired psychosocial functioning and distress, cognitive difficulties and behavior problems compared to their healthy peers (Uzark, Sauer & Lawrence, 1992; Wray, Long, Radley-Smith & Yacoub, 2001; Wray & Radley-Smith, 2005; Wray & Radley-Smith, 2006). These studies are predominantly exploratory or descriptive, have relatively small homogenous samples and originate for the most part from American or British centres. They rely primarily upon quantitative methodology, using standardized measures, and therefore possibly limit the descriptive scope of participant experiences.

The variable results of these prior studies provide a compelling case for further investigation and lead to the proposition that the breadth of impact of life changes following transplantation, such as challenges in returning to school, relationships with friends and family, and self-worth have not been fully captured. In addition, possible important factors in post-transplant adaptation and life-long adherence with follow-up regimens or other key risk factors interfering with quality of life have not yet been identified. Few studies have captured the subjective experiences of young heart transplant recipients or have sought to convey these complex experiences in a holistic
manner. This body of work addresses a significant gap in knowledge and contributes to
enhanced understanding of quality of life following pediatric heart transplantation. It is
hoped that the results will allow improvements to be made in the overall management of
pediatric heart transplant recipients that will ultimately result in improved outcomes for
this unique patient population.

1.3 Research Question and Objectives

This program of research explores the day to day experiences of pediatric heart transplant
recipients, and captures the transplantation experience from the perspective of those who
live it and create meaning from it. In an effort to encapsulate this complex experience
and to learn more about the psychosocial issues in pediatric heart transplantation, this
body of work was guided by the overarching research question, “What are the
experiences and perceptions of pediatric heart transplant recipients with respect to their
quality of life?” Exploration of this broad question was strengthened further by the
development of specific areas of focal interest, including the child’s perception of
psychosocial adjustment at school and at home, relationships with peers and family,
changes in physical appearance and physical functioning, and overall perceptions of
quality of life.

This innovative research taps the unique and subjective experiences of pediatric heart
transplant recipients and provides much needed insight into the impact of transplantation
on quality of life. The results will provide critical information for health-care
professionals treating and supporting these children. This information will lead to the
enhancement and/or development of innovative intervention strategies and clinical
protocols to more effectively improve outcomes post-transplant. Moreover,
derstanding the experiences of this distinct clinical population is crucial to the
development of future descriptive and explanatory studies addressing the biopsychosocial
impact of pediatric transplantation and overall quality of life.

1.4 Organization of Dissertation

The following is a brief overview of the content contained in the six chapters of this
dissertation.

Chapter 2 contains background information pertaining to heart transplantation, a focused
review of the historic progression of pediatric heart transplantation and the literature
exploring quality of life following pediatric heart transplantation.

Chapter 3 examines the concept of quality of life and reviews some of the controversial
issues that surround it. A description of the theoretical framework and underlying
guiding assumptions are included.

Chapter 4 contains the research design and methodology, including a review of grounded
theory, description of the participants and details of the data collection and analysis.

Chapter 5 presents the themes and core categories that emerged from the analysis. The
material is supplemented by thick description and quotes from the participants.

Chapter 6 includes a discussion of the findings, reviews the limitations and the
implications of the findings for clinical practice and future research.
Chapter 2
Heart Transplantation

2.1 The History of Heart Transplantation

The possibility of heart transplantation has intrigued medical science for many years and it is one of the most remarkable success stories of the 20th century. The imagination of the world’s lay and medical communities was captured in December 1967 when Dr. Christiaan Barnard, building on the many years of advance work performed by Dr. Norman Shumway and others, made history by performing the first human heart transplant in Capetown, South Africa. Although the recipient survived for only 17 days, Barnard’s accomplishment sparked worldwide interest in heart transplantation and spurred many centers around the world to begin prematurely transplant programs due to the prestige and publicity (Parness & Nadas, 1988). The outcomes for heart transplant recipients during the early years were poor. In 1969, an 80% mortality rate resulted for the 150 transplants performed worldwide and in 1976, 80% of heart transplant recipients died within one year of transplant (Duitsman, 1996). Rejection, infection and donor shortage attributed to such disappointing outcomes that heart transplantation was essentially abandoned by most centers by the mid 1970s (Hobbs & Sexson, 1993; Parness & Nadas, 1988).

In 1980, a resurgence in heart transplantation occurred as a result of continued research and, more significantly, the introduction of cyclosporine, a powerful immunosuppressant. The discovery of cyclosporine, a safer and more effective immunosuppressive medication, was considered a ‘wonder drug’ and revolutionized the entire field of organ
transplantation (Duitsman, 1996; Young et al., 2003). Use of cyclosporine in renal transplantation led to increased patient survival by decreasing both acute rejection and early graft loss (Bucuvalas, Campbell, Cole & Guthery, 2006). Following the advent of cyclosporine, there was renewed interest in heart transplantation. There was a virtual explosion in the number of heart transplants performed worldwide, with an increase from 24 transplants in 1976 to 4429 in 1994 (Duitsman, 1996; Taylor et al., 2008).

As survival began to improve substantially, heart transplantation gained widespread acceptance as a therapeutic option and eventually was no longer considered an experimental procedure. Among the factors that influenced the increasingly successful outcomes were increased surgical experience, development of refined surgical techniques, better donor organ preservation, improved assessment of immunologic aspects of tissue typing and histocompatibility, development of more effective immunosuppressant agents with fewer side effects, advances in controlling infectious disease and more careful selection of transplant recipients (Hobbs & Sexson, 1993; Marty & Rubin, 2006; Sigfusson et al., 1997). Heart transplantation has developed into a successful, life-preserving therapy and in many cases is now the preferred treatment for individuals with end-stage heart disease. Current survival statistics for heart transplant recipients are vastly better, with one-year and five-year survival of approximately 80% and 70%, respectively (Taylor et al., 2008). To date, survival has been improving generally as a result of reduced early mortality; however, further reductions in late mortality are necessary to achieve the goal of decades-long survival. The primary factor
limiting the ability to perform a greater number of heart transplants remains donor organ availability.

2.2 Symbolism of the Heart as a Transplanted Organ

“We tend in the medical world, to think of the heart as a pump. We’ve got to be reminded, sometimes by the patient, that the heart is an organ with a lot of mystery to it, if you will, a lot of history to it. The heart loves, the heart represents not simply that organ that sends the blood around, but that organ which we associate with some of our most wonderful human attributes. I mean love, heart as courage. We’ll talk about an athlete who has heart: identifying the heart with valiant, courageous impulses. The heart with sentiment, with affection. Do we really think that one can take out a heart, and replace it with another heart, and not set off an extraordinary chain of associations on the part of the recipient? Will my new heart be valiant? Will my new heart be loving? Am I the same person now that I have a new heart? Am I that other person?” (Rothman, 1992)

Throughout history, the heart has occupied a special place in people’s minds. It has been viewed as a potent symbol, as well as a vital organ. The heart is often regarded as the source of love, emotion and focus of personality traits. It has been defined as “the centre or source of emotions, personality attributes…the inmost thoughts and feelings; consciousness, conscience…the source of emotions…energy, spirit, resolution” (Webster’s, 1983, p. 836). The mythological qualities ascribed to the heart and its symbolic nature often complicates heart transplant recipients’ acceptance of the new organ (Bunzel, Schmidl-Mohl, Grundbock & Wollenek, 1992; Bunzel, Wollenek & Grundbock, 1992; Kaba, Thompson, Burnard, Edwards & Theodosopoulou, 2005; Rauch & Kneen, 1989; Shapiro, 1990). "It is much harder to change or abandon an age-old idea deeply rooted in religion, art and poetry… than to understand intellectually the

While the traditional images of the body as a machine and the heart as a mechanistic organ remain strong in biomedical discourses, it has been suggested that “replacing failing hearts with functioning hearts from deceased persons must be considered much more than a complex technical procedure” (Shildrick, McKeever, Abbey, Poole & Ross, 2009, p. 35). It is posited that any change to the body inevitably transforms the self; hence it is necessary to acknowledge the disturbances to embodiment and personal identity which may be associated with transplantation (Sanner, 2001; Shildrick et al., 2009). Recent innovative research endeavors explore the possible disturbances to self-identity and bodily integrity which may occur when organs are interchanged, and examine several intriguing questions, i.e. the meaning of death, the constitution of human identity, the border between individuals and between species and the kind of medical science that our society develops (Pearsall, Schwartz & Russek, 2002; Sadala & Stolf, 2008; Sanner, 2001, 2005; Shildrick et al., 2009).

2.3 Pediatric Heart Transplantation

The first successful infant heart transplant was performed by Dr. Leonard Bailey in the United States, in November 1985. This groundbreaking event marked the beginning of the modern era of pediatric heart transplantation and propelled the pediatric transplant world forward (Suddaby, 1999). In the last decade heart transplantation has proven to be an effective and accepted therapy in pediatric patients with lethal heart disease.
Transplantation is now recognized as a successful treatment option for children with end-stage heart failure or inoperable congenital cardiac defects. Congenital heart disease is the most common indication in children younger than one year of age, while in children older than one year of age cardiomyopathy is the most common diagnosis (Kirk et al., 2009). One-month, one-year, five-year and ten-year survival statistics are high, approximately 99%, 95%, 75% and 65%, respectively (Kirk et al., 2008). With increased survival, the annual number of pediatric heart transplants performed worldwide has increased from approximately 11 transplants in 1982 to a reported 450 transplants in 2008, with the largest increase being in newborns and infants (Kirk et al., 2009). Since 1982, more than 8,058 pediatric patients have received heart transplants (Kirk et al., 2009). As with adult heart transplants, the availability of donor organs continues to limit the number of children undergoing heart transplantation.

Children or adolescents referred for heart transplantation are faced with a very serious, imminently terminal disease, for which there is usually no other treatment available. The catastrophic nature of such a life-threatening disease may make transplant, an intervention that raises hope for prolongation of life, amelioration of symptoms and improved quality of life, an appealing therapeutic pathway. The dramatic impact that transplantation may have is emphasized in Bernstein’s (1977) statement that transplant “represents an instance in medicine when a child returns from a terminally ill state to an active state of health” (p.145). Paradis, Freese and Sharp (1988) implied that transplantation offers a “cure…obtainable because surgeons have overcome major technical obstacles and cyclosporine has made the management of rejection easier”
However, others argue that transplantation does not represent an actual cure for the recipient, but rather the exchange of one chronic, imminently lethal illness for a longer-term, chronic one that is more easily manageable (Berg, 2002; Gabrys, 2005, Green, Ray & Gance-Cleveland, 2006; Hobbs & Sexson, 1993). Transplantation is a transition from an often chronic and life-threatening disease to a second chronic condition – living with and caring for a transplanted heart (Young et al., 2003).

The clinical demands of post-transplant care are wide-ranging, with special considerations for pediatric recipients. Along with the normal challenges of growth and development, children and families must continuously juggle numerous life-long illness-related stressors. Unique demands are placed upon the child or adolescent and family after a heart transplant, including:

- **monitoring for life-threatening complications** - Children may require frequent outpatient visits, regular blood tests, routine intermittent cardiac biopsies for surveillance of rejection and on-going investigations, sometimes involving invasive procedures or surgical interventions. These investigations monitor life-threatening complications such as infection, hypertension, diabetes mellitus, hyperlipidemia, osteoporosis, renal dysfunction, cardiac allograft vasculopathy and malignancies (Boucek et al., 2004, 2007).

- **intensive treatment protocols** – Children require life-long immunosuppressive medications and other medications to manage the side-effects of immunosuppressants, such as magnesium supplements and cholesterol lowering agents (Gabrys, 2005). Necessary medications may be perceived as
a burden, and the side-effects of the medications may result in body image issues for recipients, thereby increasing this burden. The potentially disfiguring side-effects of the medication regimen may include excessive hair growth, gingival hyperplasia, mild tremors, growth retardation, osteoporosis, acne, truncal obesity and cushingoid facies (Gabrys, 2005; Hobbs & Sexson, 1993). Some post-transplant medication may also result in behavioural symptoms including increased irritability, argumentativeness, tiredness and verbosity, among others (Hobbs & Sexson, 1993).

- repetitive stressful hospitalizations – Many children require multiple hospitalizations both prior to and after transplant. Hospitalization is stressful because of separation from family and peers, loss of control, loss of privacy, disruption in school, social and recreational activities and potentially painful procedures such as phlebotomy and cardiac catheterization (Gabrys, 2005; Green et al., 1996).

In summary, the post-transplant regimen is complicated by the lifelong necessity of taking numerous medications, unwelcome side-effects of the medications and intensive medical follow-up. Failure to comply with this complex and occasionally noxious post-transplant regimen may result in organ loss and possible death. Heart transplant recipients and their families also have to deal with the persistent shadow of possible graft failure and perhaps re-transplantation. These constant threats place the patient and his or her family in a situation of chronic uncertainty and unpredictably.
Heart transplantation, though life-saving, is not curative; transplant recipients and their families face innumerable post-operative physical and psychological stresses. It constitutes a major surgical procedure necessitating intensive medical support and follow-up. However, without transplantation, the prognosis for many children with congenital heart disease or cardiomyopathy is extremely poor, rendering them at risk for chronic illness with a drastically reduced life expectancy. Despite its limitations, pediatric heart transplantation continues to be an innovative and rapidly evolving therapeutic intervention offering hope for survival, rehabilitation and an improved quality of life to children who would have died of heart disease.

2.4 Quality of Life following Pediatric Heart Transplantation

In the field of pediatric heart transplantation the investigative issues that have been most emphasized in past years pertain to risk factors for mortality and morbidity, yet with improved medical outcomes, current research has shifted toward understanding and enhancing quality of life. In addition to the preservation of life, the goal of transplantation is also an improved quality of life for pediatric recipients. Although data regarding survival have justified the continued use of heart transplantation in children, there is a paucity of published data regarding the quality of life of these children. The psychosocial effects on children who undergo heart transplantation and their long-term psychological and social functioning remains unclear.

A handful of early studies utilized functional status to evaluate the quality of life of pediatric heart transplant recipients. In general, research indicated that quality of life
after transplant improved and transplant recipients experienced a much improved physical status subsequent to recovery from the transplant process. The literature reported that post-operatively children were active and could generally return to age-appropriate developmental, educational, social and recreational activities (Lawrence & Fricker, 1987; Serrano-Ikkos et al., 1999; Uzark et al., 1992). Improvements in physical condition were mirrored by higher self-esteem and a more positive attitude about capabilities (Wray et al., 1992). In early retrospective clinical chart reviews, researchers reported that 89% to 100% of pediatric heart transplant recipients participated in or were capable of participation in normal activities for age and “lead an active and satisfying life” (Pennington et al., 1985; Sigfusson et al., 1997). The quality of life of seven pediatric heart transplant recipients was assessed by Lawrence and Fricker (1987) and findings suggested that the children had “adequate or improved functioning” and were able “to return to normal lifestyles” and “adapt sufficiently” to the experience of transplantation. Uzark et al. (1992), in a multicenter study of 49 pediatric patients, revealed that most children experienced a dramatic improvement in functional status following heart transplant. Ninety-three percent were attending school and participating in recreational activities including swimming, biking, skateboarding, skating, skiing, baseball, volleyball and tennis. In two studies by Wray et al. (1994 & 2001) examining the behaviour and cognitive functioning of 65 and 81 children who had undergone heart or heart-lung transplantation, most children had returned to activities appropriate for their age and the majority had settled back into school, with academic attainments within normal limits.
With a focus on psychosocial outcomes as proxies for quality of life, DeMaso et al. (1995) examined the psychological functioning of 23 children and adolescent heart transplant recipients utilizing clinician ratings on the Children’s Global Assessment Scale. It was found that the majority of these pediatric patients (78.3%) demonstrated improved psychological functioning within the normal range after their transplant. In a longitudinal follow-up study, DeMaso et al. (2004) described the almost decade-long maintenance of the improvement in psychological functioning. Most patients (73%) who had survived almost a decade after heart transplant showed improvement in overall emotional and psychological functioning. In another longitudinal study, Serrano-Ikkos et al. (1999) examined psychosocial outcomes in 23 heart and 21 heart-lung transplant recipients, aged 5 -17 years, and found significant improvement in physical health and psychosocial functioning 12 months after transplant. These results are consistent with Wray et al. (1992), whose prospective evaluation of 28 heart or heart-lung transplant recipients found that psychosocial functioning (e.g. cognitive development and ability, behaviour, self-esteem) was substantially better following transplant and parent and teacher assessments indicated a marked reduction in the prevalence of behavioural problems both at home and school. Spurkland, Bjorbaek and Hagemo (2001) longitudinally assessed 12 patients and found that overall physical and psychological conditions improved two years following heart or heart-lung transplant, based predominantly upon parent proxy reporting. Pollock Bar-Ziv et al. (2003) examined the self-perceived quality of life of eight heart transplant recipients, aged 10 – 18 years; results demonstrated excellent overall quality of life and psychologic well-being. In a rare qualitative study, Green et al. (2007) sought to describe the quality of life of eleven
school-aged heart transplant recipients aged 6-12 years and found that most of the children described their lives in positive terms, such as “mostly good” or “fun” and they generally valued the normal aspects of life.

The results of these studies support the adaptive potential of children and adolescents following heart transplantation and indicate that the majority of pediatric recipients appear capable of healthy physical and psychological functioning. However, despite significant improvements in functional status, quality of life and psychosocial outcomes, results of some studies suggest that a significant minority of patients do experience psychological difficulties at some stage after transplantation. With the on-going presence of a chronic illness, daily treatments, unpleasant side-effects and the need for continuous medical supervision, pediatric transplant recipients face significant physical and psychosocial stresses and threats to their adaptation.

Further to this, in a synthesis review of psychological outcomes of heart transplantation in children, Todaro, Fennell, Sears, Rodrigue and Roche (2000) reported that a proportion of recipients are at risk for psychological difficulties. Findings suggested that a sizable number of children and adolescents, much greater than in the general population, experience emotional adjustment and psychosocial impairment following heart transplantation (Todaro et al., 2000). Specifically, pediatric heart transplant recipients were found to be at increased risk of experiencing psychological distress, such as anxiety, depression, behavioural disorders and decreased social competence, compared to normal, healthy peers (Todaro et al., 2000). Similar findings have been reported by Wray and
Radley-Smith (2005, 2006, 2007) in longitudinal studies assessing psychological functioning in children after heart transplant. In addition, there appears to be a higher prevalence of psychiatric illness among pediatric heart transplant recipients compared with the general population, with approximately 18% experiencing a psychiatric disorder (Serrano-Ikkos et al., 1999; Spurkland et al., 2001). The emotional well-being of some pediatric transplant recipients may be impacted by the stressors associated with transplantation, resulting in symptoms of negative affect, decreased social competence, and behaviour problems (Todaro et al., 2000). These findings suggest that for a number of patients, as least, there may be difficulties coping with the demands of pediatric heart transplantation, as some patients continue to display impairment in their psychosocial functioning.

It may be concluded that while problems do remain, heart transplantation appears to result in an improved quality of life for pediatric patients, and the majority of children and adolescents are capable of healthy psychosocial functioning following heart transplantation. However, it is vital to note that the majority of the literature on quality of life following pediatric heart transplantation, including the studies reviewed here, have important methodological limitations. Studies vary with respect to the definition or operationalization of the term quality of life, the design of the study (prospective vs. retrospective, cross-sectional vs. longitudinal), the time of the assessment relative to transplant and the age range of patients in the sample. Research samples have been comprised of relatively small proportions of patients from single transplant centres, and in some studies heart and heart-lung transplant recipients have been examined as a
unitary group, although controversy exists as to whether these groups are readily comparable. In addition it is not clear to what extent results from the United States and Britain, where the majority of reports originate from, are applicable to a Canadian population. Much of the research cited relied heavily on the opinions or assessments of proxy informants (parents, teachers or health-care professionals), therefore the subjective experiences of transplant recipients at best, may not be fully ascertained, or, at worst, are not captured and children’s quality of life is misinterpreted. There is as yet little information available about the child’s or adolescent’s own perception of their psychological adaptation and quality of life following transplantation. To date, the majority of studies are quantitative and have utilized a variety of different assessment tools and measures, hence the validity of current quality of life assessment is in question. Quality of life studies after pediatric heart transplantation using a qualitative approach have been sparse, thereby limiting researchers’ and clinicians’ comprehensive understanding of the personal, nuanced realities and quality of life of heart transplant recipients.

In sum, the literature on quality of life following pediatric heart transplantation is scarce, heterogeneous and limited by ill-defined and varying conceptualizations of quality of life from which theoretical orientations are unclear. Current conceptualizations emerge from a range of methodologies and instruments, and existing studies are hindered by small samples, use of single proxy informants and notable gaps in design including a lack of qualitative and longitudinal prospective studies.
Chapter 3
Theoretical Framework and Quality of Life

3.1 Guiding Frameworks

“A theory is an organized statement of ideas about the world” (Payne, 2005, p. 5). Theoretical frameworks provide concepts for understanding human behaviour with respect to growth, development and individual and interpersonal functioning. Social and psychological theories about human behaviour in the social environment are ever expanding and reflect the explosion of knowledge over the past centuries (Bogo, 2006). The wider theoretical perspective of ecological theory underlies this program of research, within this perspective, the conceptual framework of quality of life represents a more focused lens to explore the experiences of adolescents who have undergone heart transplantation.

3.2 Ecological Perspective: ‘person-in-environment’

An ecological model offers a framework for the analysis of human development and provides a basis for exploring the relationship between individuals and their environment. The ecological perspective embraces a holistic view of individuals and environments, assuming that neither can be fully understood outside of the context of its relationship with the other (Bronfenbrenner, 1979, 2005). That relationship is characterized by dynamic, continuous reciprocal exchanges or transactions, in which individuals and environments influence, shape and sometimes change each other over time (Bronfenbrenner, 1979; Germain & Bloom, 1999; Gibson, 1979). Ecological theory encompasses the personal characteristics of an individual (e.g. biological, psychological...
and spiritual), as well as the characteristics of the environment(s) in which the individual interacts (e.g. physical, social, political, cultural and economic) and emphasizes the importance of the interconnectedness or reciprocal interplay between each of them.

A basic premise of ecological theory is the position that the environment of greatest relevance for the understanding of development is reality, not as it exists in the so-called objective world, but as it appears in the mind of the individual (Lewin, 1942). The emphasis is on how an environment is perceived by the individuals who interact with it. It is impossible to understand human development solely from the objective properties of an environment without reference to its meaning for the individuals in the setting (Bronfenbrenner, 1979, 2005). The focus is not on the traditional psychological processes of perception, motivation, thinking or learning, but on their content – what is perceived, desired, feared, thought about or acquired as knowledge, and how the nature of these perceptions changes as a function of an individual’s exposure to and interaction with their environment. Thus, development is defined as an individual’s evolving concept of the ecological environment, and his or her relation to it, as well as his/her growing capacity to discover, sustain or alter its properties (Bronfenbrenner, 1979, 2005).

The ecological perspective points to theoretical systems that provide a useful understanding of individuals and their environments. An individual, the environment(s), and the relations between them are conceptualized as a set of nested systems, each embedded within the next (Bronfenbrenner, 1979, 2005). These interrelated systems are referred to as the micro-, meso-, exo-, and macrosystems. A microsystem is a pattern of activities, roles and interpersonal relations experienced by the developing individual in
the immediate social setting with particular physical and material characteristics. An example of a microsystem is the family. A *mesosystem* comprises the interrelations among two or more settings in which the developing individual actively participates. Examples of mesosystems include school and neighbourhood peer groups. An *exosystem* refers to one or more settings that do not involve the developing individual as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing individual. An example of an exosystem is an institution or organization, such as a local school board. A *macrosystem*, or *cultural milieu* as it is sometimes called, refers to the overarching patterns of attitudes, practices, belief systems and ideology common to a particular society. These are wider system factors affecting, but somewhat remote from, the everyday experiences of the individual. The ecological environment is thus conceived topologically as a nested arrangement of systems, with the macrosystem encompassing the microsystems, mesosystems and exosystems.

In sum, the relations between an individual and his or her active and multi-system environment constitute the driving force of the ecological model for enhancing the course of human life (Bronfenbrenner, 2005). The transactions between the individual and his or her environment(s) that function to benefit both, should be, from the perspective of the ecological model, the focus of efforts to improve human development. “Indeed, the plasticity of these relations, and thus the ability to maximize the possibility for adaptive development…, defines the essence of being human” (Lerner, 2005, p. xix).
Ecology of Childhood

Children are embedded within multiple systems including family, neighbourhood, peer groups, the classroom and the community. A child usually lives in a family. A family lives in a neighbourhood. The neighbourhood may encompass a peer group. Children typically attend school and later may work in the community. These interdependent systems in children’s lives can be conceptualized as an ‘ecology of childhood’ (Fraser, 2004). Developmental theorists have asserted that the relationship between children and their environment is complex, involving simultaneous mutual influence among children and multiple systems (Matza, Swensen, Flood, Secnick & Leidy, 2004). According to this theoretical perspective, children are viewed as active agents who engage with their environment (Chawla & Heft, 2002; Matza et al., 2004). They exert an influence upon their environment while simultaneously being shaped by their environment. This bidirectional influence can have long-term effects on children’s development and has been demonstrated through empirical research on children’s interactions with parents, siblings, peers, teachers, coaches and religious leaders (Fraser, 2004; Matza et al., 2004). This theory also posits that the ecological environment is different and possibly more important for children than for adults, in that children have less power than adults to make significant changes to their environment, lacking the ability to engage fully with aspects of their environment in a selective, self-directed and purposeful manner (Matza et al., 2004).
Framing Quality of Life within Ecological Theory

Ecological theory offers a conceptual structure through which to enhance our understanding of the essential meaning of quality of life (Brown, 1997; Goode, 1994; Renwick, Brown & Nagler, 1996; Schalock, 1996, 1997). An ecological approach views quality of life as arising out of the unique and continuous interactions between an individual and his or her environment. The concept of quality of life is best understood in a holistic way (Timmons, 1997). It is perceived as a complex, integrated whole, recognizing the continuous, dynamic reciprocal relations between individuals and their environments (Renwick & Brown, 1996; Timmons, 1997). While characteristics of individuals and their environments continually influence each other to varying degrees, these factors do not exert their influence in isolation but rather through a complex matrix characterized by their inter-connectedness (Renwick & Brown, 1996). Thus, quality of life is a fluid and flexible phenomenon that is uniquely experienced by each individual (Renwick, Brown & Raphael, 2000).

There is emerging international consensus that to understand the multi-dimensional concept of quality of life, it must be put it into the full person-in-environment configuration (Brown, 1997; Germain & Bloom, 1999; Goode, 1994; Renwick et al., 1996; Schalock, 1996, 1997). An ecological standard of quality of life focuses on the degree of ‘fit’ between a person and his or her environment (Bach & Rioux, 1996). The quality of a person’s life is intimately bound up in their connectedness to their environment. A high quality of life is an emergent property of the quality of the relationship between a person and their environment and is characterized by the extent to
which the person is actively engaged with (attending to, interacting with, participating in) his or her environment (Felce, 2000). All the relevant systems and subsystems that may play a part in influencing ‘quality’ within people’s lives must be considered. “One cannot separate the quality of a person’s life from the influence that factors at the micro-, meso-, exo- and macrosystem levels have on that person’s perception of a life of quality” (Keith & Schalock, 2000, p. 372). A complete picture of quality of life recognizes the interrelationship among multiple systems at various degrees of immediacy to the person and takes into account their collective impact on that individual’s experiences. The broad and inclusive nature of the ecological model allows us to understand better the diversity of influences that shape one’s perceived quality of life.

Framed within the person-in-environment perspective, a novel theoretical-philosophical approach to quality of life has emerged that focuses on three fundamental areas of life common to the human condition and essential dimensions of human experience (Wallander, Schmitt & Koot, 2001; Woodill, Renwick, Brown & Raphael, 1994). These broad areas of life arise out of the ongoing interaction between persons and environments, and are referred to as being, belonging and becoming (Renwick & Brown, 1996). Being encompasses the most basic aspects of who people are as individuals (e.g. physical being, psychological being, spiritual being). Belonging is concerned with the fit between individuals and their various environments (e.g. physical belonging, social belonging, community belonging). Becoming focuses on the purposeful activities in which individuals engage in an attempt to realize their goals and aspirations (e.g. practical becoming, leisure becoming, growth becoming). An individual’s quality of life
is “determined by both the relative importance or meaning attached to each dimension and the extent of their enjoyment in each area” (Renwick & Brown, 1996, p. 84). While perceived *importance* and *enjoyment* are considered to be the major factors determining quality of life, quality of life is influenced by two other factors: *control* and *potential opportunities*. The former refers to “individuals’ perceptions concerning how much control they can exert with respect to the important possibilities of their lives” and the latter refers to “individuals’ perceptions about the extent of their potential opportunities…for change or enhancement” (Renwick & Brown, 1996, p. 84).

This framework makes a significant contribution to the theoretical knowledge on quality of life (Wallander et al., 2001). It offers a broad grounded perspective that integrates important elements of the concept of quality of life in an innovative way. The approach is a versatile model for conceptualizing quality of life in the context of health care and provides a guiding framework for studying quality of life (Renwick & Brown, 1996).

### 3.3 Quality of Life

Advances in medical research have resulted in significantly improved survival rates for many pediatric illnesses and a shift in children’s health care from the diagnosis and management of infectious diseases and other acute conditions to the prevention and control of chronic conditions (Upton et al., 2008). With these epidemiological changes there is increasing recognition that mere survival statistics are no longer a ‘gold standard’ when considering the efficacy of medical intervention. The considerable morbidity factors that may accompany many medical treatments and ‘heroic’ interventions have
resulted in the demand for more comprehensive and holistic outcome measures (Eiser & Morse, 2001a, 2001b). This orientation is in keeping with the medical precept of *primum non nocere*, which means that the benefits of treatment must be greater than the suffering that may be entailed (Greer, 1984).

Awareness is growing that medical parameters such as mortality and morbidity are not the only important outcome variables to be considered systematically. Although necessary and valuable, these outcome measures do not reflect the patient’s overall well-being and do not take into account subjective evaluation of health status and quality of life (Eiser & Morse, 2001a, 2001b; Vogels et al., 1998). Attention to arguments of this kind has resulted in a ‘paradigm’ shift in criteria to evaluate health outcome (Eiser & Morse, 2001a, 2001b). There has been a departure from measuring treatment outcome based on purely biochemical or physiological parameters to one that focuses on a more sensitive and comprehensive assessment of patient perception and overall quality of life (Burra & De Bona, 2007). Conventional outcomes need to be integrated with patients’ opinions of their health, reflecting how they really feel and how much their diseases affect their way of life (Burra & De Bona, 2007). Consequently, this shift in focus from survival to quality of life has provided momentum for quality of life research in pediatric medicine.
The Concept of Quality of Life

There has been a tremendous growth of interest in the concept of quality of life in recent years. To appreciate fully the importance of this concept, it is helpful to consider its intrinsic meaning. Quality is generally understood to mean excellence or superiority, and is associated with human characteristics and positive values such as happiness, success, wealth, health and satisfaction; of life indicates that the concept concerns the essential aspects of human existence (Lindstrom, 1992). From a semantic point of view, the concept of quality of life encompasses the values that are central to human life and that constitute the essence of our existence (Lindstrom, 1992). Although the general meaning of quality may be understood, the specific meaning, when applied to people’s lives, varies considerably among individuals and groups of people. “It is highly unlikely that any two people, from their own perspectives, think of excellence (and) superiority…in precisely the same way…the essential meaning of quality may be understood by all, but when it is related to real people’s lives, it is interpreted in any number of ways” (Brown, 1994, p.ii).

Contentious Issues

The concept of quality of life is not new; the debate of what constitutes well-being or happiness can be traced back to the writings of Plato and Aristotle (Ferrans, 1990; Mackie, 1977). However, during the last few decades quality of life-related research and application have increasingly become a focus in the field of health care (Goodinson & Singleton, 1989; Keith & Schalock, 2000). The tremendous growth in the number of publications on quality of life that have appeared in the health literature in the past few
years has been exponential and underscores the increasing interest in, and attempts to understand, quality of life as a concept (Cummins, 1997; Renwick et al., 2000; Taillefer, Dupuis, Roberge & Le May, 2003). The significant attention that the concept of quality of life is currently receiving in the literature has been termed the ‘quality revolution’ (Schalock, 1994, p.2)

There are several issues and challenges that have arisen in quality of life research which have generated substantial amounts of controversy and debate. These relate primarily to issues surrounding conceptualization, assessment and measurement, reflecting the lack of consensus on definition, interpretation and methods of measuring life’s quality (Taillefer et al., 2003). Challenges pertaining to conceptual issues include how to define quality of life and how to select which domains or dimensions should be considered. Attention must be given to the assessment, the appraisal of information to describe or better understand an issue, of quality of life including reasons it should be performed. Finally, issues implicit in measurement, the process by which the attributes or dimensions of an object, event or condition are determined, of quality of life include deciding which parameters should be measured and from whose perspective valuations should be made. These three issues will be considered in more depth in the following section.

Conceptualization

The conceptualization of quality of life began with the World Health Organization’s definition of health as “a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity” (WHO, 1948, p.1). While this commonly
cited definition of health has remained the cornerstone of the quality of life construct, many varying definitions of quality of life have been proposed over the years. In excess of 100 definitions of the term ‘quality of life’ have been identified in the literature (Cummins, 1997). Most broad definitions of quality of life encompass concepts of happiness and satisfaction (Molzahn, Northcott & Hayduk, 1996). For example, quality of life has been defined as “the perceived degree of overall satisfaction or dissatisfaction of an individual regarding his/her life in general or his/her life situation” (Molzahn et al., 1996, p. 427), “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (Ferrans, 1990, p.15), “the degree of overall life satisfaction that is positively or negatively influenced by an individual’s perception of certain aspects of life that are important to them” (Moons, Van Deyk, Budts & De Geest, 2004, p. 1067) and “an individual’s overall satisfaction with life, and one’s general sense of personal well-being” (Spilker, 1990, p. 3). Others have suggested, as a more active aspect, that quality of life is “the satisfaction of an individual’s values, goals and needs through the actualization of their abilities or lifestyle” (Emerson, 1985, p. 282) or “the degree to which a person enjoys the important possibilities of his or her life” (Renwick et al., 1994, p. 35). Brown (2000) noted that “other definitions contain concepts about discrepancies, and examine the difference between what individuals have and what they actually require and want” (p. 352). Quality of life is “the perceived differences between an individual’s hopes and expectations and their present experiences” (Calman, 1987, p. 7) or “the discrepancies between a person’s achieved and unmet needs and desires” (Brown, Brown & Bayer, 1994, p.41).
Although a precise and universally accepted definition of quality of life has yet to be framed, there is growing consensus around two fundamental concepts that are inherent in most definitions (Eiser & Morse, 2001a, 2001b; Matza et al., 2004). First, quality of life is primarily subjective, and should therefore be assessed from the patient’s perspective whenever possible. Individuals have their own unique perspective on quality of life, which depends on present lifestyle, past experience, hopes for the future, dreams and ambition. Second, quality of life is generally conceptualized as a multidimensional construct encompassing several broad domains. The World Health Organization (1995) suggested that the concept of quality of life reflect the following six core dimensions: physical health, psychological state, level of independence, social relationships, environment and spirituality or religious or personal beliefs. The most widely-used quality of life domains include physical, psychological and social functioning and well-being (Arnold et al., 2004; Burra & De Bona, 2007; Matza et al, 2004). Happiness and/or satisfaction with particular quality of life domains can vary greatly between individuals; moreover, for each individual the relative importance of domains varies over a life-time and each does not impact equally on quality of life (Ferrans & Powers, 1985).

A term that has gained considerable usage in recent years is ‘health-related quality of life’. It has been argued that within the context of health care, it is important to distinguish ‘health-related quality of life’ from broader concepts of ‘quality of life and general well-being’. The concept of health-related quality of life is typically used in a narrow sense within the field of medicine among those who are primarily interested in the
Quality of life is thus a complex, multifaceted concept which continues to defy consensual definition. While the absence of a unique definition has been criticized, the value of the construct of quality of life is not diminished. Quality of life can seem unscientific compared with traditional endpoints, thus translating this nebulous concept...
into empirical terms has proven to be difficult. Despite these conceptual challenges, the subjective notion of quality of life nonetheless offers potentially tremendous value.

Assessment

There has been a dramatic increase in the assessment of quality of life in an effort to improve pediatric patient health and well-being and to determine the value of health-care services (Drotar, 1998; Varni, Libers & Burwinkle, 2007). Quality of life assessments have been progressively acknowledged as essential health outcomes in pediatric clinical research and health service evaluation (Varni et al., 2007). This recognition and interest in quality of life assessment stems from both a concern for the quality of the health-care process and the desire to monitor ever more closely the outcome of medical care and intervention (Leplege & Hunt, 1997).

Assessments of quality of life have several important uses in research and the comprehensive care of children and adolescents with chronic illness. First, quality of life assessments provide descriptive information regarding the health status of children with chronic health conditions. There is increasing emphasis on the value and need to understand the child’s own perception of illness and its effect on day-to-day life (Varni et al., 2007). Second, evaluation of children’s quality of life is used to facilitate the identification of children’s level of morbidity, including those at risk for psychological or behaviour problems (Eiser, 1995; Mulhern et al., 1989). Third, there is a body of literature that links quality of life assessments to improved clinical knowledge and decision-making by using these assessments to yield understanding about the
consequences and experiences associated with different illnesses from children’s and adolescents’ perspective. Including quality of life outcomes expands the scope of evaluations of the quality of medical care by allowing assessment of the impact of the condition and related treatments on the child’s functioning and lifestyle (Bowling, 1995; Spieth & Harris, 1996). Assessments of quality of life are potentially useful in comparisons of alternative treatments or may assist when making ‘end of life’ decisions – in particular, when it is appropriate to withhold treatment because the anticipated quality of life is very poor (Eiser, 1997).

Measurement

The ‘wild growth’ in the field of quality of life has resulted in the development and output of various instruments (Taillefer et al., 2003). Due to the vast number of instruments used to measure quality of life, it has proven difficult to compare, generalize or replicate findings (Burra & De Bona, 2007). To date there remains no consensus about the ‘gold standard’ instrument to measure quality of life (Burra & De Bona, 2007; Molzahn et al., 1996). There have been concerns raised about the quality of many of the available instruments and the feeling that many have been constructed on an *ad hoc* basis with little regard for their psychometric properties (Kinney, 1995; Taillefer et al., 2003).

Numerous generic and disease-specific indices and indicators have been developed that attempt to assess children’s quality of life. Generic measures are designed to be broadly applicable across many types of diseases, treatments and groups of individuals. Generic measures permit comparisons across interventions and diagnostic conditions, and
facilitate the integration of research findings across various populations (Drotar, 1998, Matza et al. 2004). In addition, data can be compared to general pediatric population norms to determine the impact of disease on quality of life (Matza et al., 2004; Eiser & Morse, 2001a, 2001b). Examples of some more commonly utilized generic measures include the Child Health and Illness Profile (Starfield et al., 1993, 1995), the Child Health Questionnaire (Landgraf, Abetz & Ware, 1996), the Child Quality of Life Questionnaire (Graham, Stevenson & Flynn, 1997), the Pediatric Quality of Life Questionnaire (Varni, Seid & Rode, 1999), and the Quality of Life Profile – Adolescent Version (Raphael, Rukholm, Brown & Hill-Bailey, 1996). Condition or disease-specific measures take into account aspects of disease and treatment that are relevant to a specific medical condition. Such measures may be more sensitive to changes in a child’s condition or status, and they tend to be more effective than generic measures at detecting treatment or intervention effects (Drotar, 1998; Matza et al., 2004). Disease-specific measures may be more responsive than generic measures to clinically relevant aspects of children’s lives related to a specified condition, and therefore may have greater salience for clinicians (Eiser & Morse, 2001a). Disease-specific pediatric measures are available for a variety of medical conditions, including asthma (Childhood Asthma Questionnaire – Christie, French, Sowden & West, 1993; French, Christie & Sowden, 1994; Pediatric Asthma Quality of Life Questionnaire - Juniper et al., 1996), cancer (Pediatric Oncology Quality of Life Scale – Goodwin, Boggs & Graham-Pole, 1994; Pediatric Cancer Quality of Life Inventory – Varni, Katz, Quiggins & Friedman-Bender, 1998; Varni, Katz, Seid et al., 1998), and epilepsy (Quality of Life in Epilepsy – Wildrick, Parker-Fisher & Morales, 1996).
An important issue in measuring children’s quality of life involves the problem of which aspects or dimensions to include. Among the dilemmas this question raises is the problem of deciding from an adult perspective what constitutes ‘quality of life’ in children, whose life experiences and daily activities differ substantially from those of adults (Rosenbaum & Saigal, 1996). Adults may vary in their perspectives, depending on whether they are parents, caregivers, policy-makers or community citizens. Assumptions about what constitutes quality of life can lead adults to consider features of children’s daily life that may or may not be important to the children or provide a valid reflection of the children’s life experiences (Rosenbaum & Saigal, 1996). A major limitation of most of the available measures of quality of life for the general population of children is that they are all largely based on the conceptualizations of adults.

Another dilemma in trying to measure quality of life in children involves the perplexing issue of whose perspective on children’s quality of life should be sought. Traditionally, there have been “few attempts to understand children’s lives in their own terms and take children’s own words at face value, as a primary source of knowledge about their experience” (Morrow & Richards, 1996, p.97). Instead, the child’s world is often understood and hidden in the ideological apparatus of the family, or more specifically, the voices of parents. We learn not about children’s perspectives, but rather about adults’ concepts of childhood (Oakley, 1994). There is increased recognition of the need to include children’s own views about their health, psychological state and treatment ideas within any health assessment and to provide them with the opportunity to speak for
themselves (Eiser & Morse, 2001a; Rosenbaum & Saigal, 1996). The United Nations Convention on the Rights of the Child (Quinn et al., 2002) and A Canada Fit for Children (Social Development Canada, 2004), Canada’s response to the United Nation’s document, uphold the rights of children to participate in matters affecting their well-being.

To the extent that quality of life is subjective, there are strong arguments in favour of eliciting data directly from children wherever possible (Burra & De Bona, 2007; Eiser & Morse, 2001a; Varni et al., 2007). Children are recognized as active and competent individuals, who are capable of speaking for themselves and of providing reliable information about their situation (Cousins & Milner, 2007; Lloyd-Smith & Tarr, 2000; Mishna, Antle & Regehr, 2004). There is growing awareness that children’s voices should be heard and their opinions sought in matters that affect their lives, resulting in a demand to place children’s viewpoints and voices at the centre of research pertaining to their health and well-being (Cousins & Milner, 2007; Mishna et al., 2004; Morrow & Richards, 1996).

A growing body of literature suggests that it is not possible for anyone else to have insight into a child’s unique experiences, considering the frequent divergence of perceptions and values between a child and another individual (Eiser & Morse, 2001a; Raphael, 1996; Rosenbaum & Saigal, 1996). This trend underscores that adult ‘proxies’, such as parents, clinicians or teachers, are unlikely to be able to represent children’s worlds accurately, no matter how well-intentioned or informed the adult (Mahon,
The likelihood is that the relative values and importance of various quality of life domains are quite different to children than to adults, simply as a function of different life stages and experiences (Rosenbaum & Saigal, 1996). While parents’ views about the child’s quality of life may be useful, interesting and indeed valid, it is important to remember that parental reports represent a proxy response about their child’s quality of life. There are no reasons to suppose that they can be used as substitutes for the child’s own views (Eiser & Morse, 2001a; Jenney & Campbell, 1997; Varni et al., 2007). Parents’ views will be based on different information and expectations, and will reflect different experiences (Vogels et al., 1998). They will also be affected by additional life stressors and their own mental and physical health (Eiser & Morse, 2001a). As well, clinicians are influenced by their own personal reference points and use their own past experience with similar patients as guidelines (Vogels et al., 1998).

The need for self-assessment by the child is supported by the inconsistency observed between assessments made by children and proxies (Burra & De Bona, 2007; Krol et al., 2003; Varni et al., 2007). It is well-documented in the literature that information provided by proxy-respondents is not equivalent to that reported by the patient (Burra & De Bona, 2007; Eiser & Morse, 2001; Krol et al., 2003; Varni et al., 2007). In a meta-analysis of 14 studies evaluating the agreement between child and proxy reports in chronically ill populations, Eiser and Morse (2001a) found greater agreement between children’s and parents’ reports of observable behaviours such as physical functioning than of non-observable functioning such as emotional or social quality of life. For
example, while parents know directly whether their child needs glasses to see well or requires help with mobility, their judgments about emotion or pain are based on their interpretation of their child’s behaviour, and thus provide only indirect accounts of quality of life (Rosenbaum & Saigal, 1996). It has been shown that children’s behaviour may vary according to the setting (e.g. home or school) (Achenbach, McConaughy & Howell, 1987), thus parents’ reports may be valid but incomplete accounts of children’s status (Rosenbaum & Saigal, 1996).

Many conceptions of quality of life assess a range of less observable functional components, rendering this concept difficult to predict or interpret unless actually having experienced that reality. Given the potential for significant discrepancies between child and proxy assessments of quality of life, it is argued that self-assessment by the child is preferable whenever possible (Burra & De Bona, 2007; Eiser & Morse, 2001a; Jenney & Campbell, 1997; Varni et al., 2007). Relying on proxy informants may result in incomplete assessments to the extent that the child’s subjective experience and perceptions of quality of life may be overlooked. Although information obtained from proxies is valuable, it should be included as a secondary outcome measure to complement a child’s self-assessment, not to serve as a convenient substitute (Varni et al., 2007).

While considering the perspectives of children in evaluating their quality of life is extremely important and innovative, the very children for whom it is most desired to obtain direct measures are often unable to participate due to severe disabilities. When it is not possible to elicit quality of life information from a child due to illness or a lack of
cognitive or communication skills, the perspectives of parents are valuable in enabling the assessment of every child in population-based studies. While there may be a degree of distortion in parental responses about their child’s quality of life, parents nonetheless are usually an excellent and knowledgeable source of information about their child (Rosenbaum & Saigol, 1996).

In summary, despite the numerous unresolved conceptual and methodological concerns, quality of life issues have become steadily more important in pediatric health-care practice and research over the past decade (Burra & De Bona, 2007; Drotar, 1998; Upton et al., 2008; Peterson et al., 2005; Varni et al., 2007). There is growing interest in evaluating interventions and assessing treatment outcomes with the hope of obtaining a thorough understanding of their effect on children’s quality of life and well-being. Quality of life is a potentially transformative concept that has the power to redirect the focus from a piecemeal view of the issues that influence a child’s life to a holistic perspective on the lives of children (Renwick et al., 2000). The attainment of excellent quality of life for children is at the heart of pediatric medicine. Whether defined as ‘life satisfaction’, ‘attained goals, hopes or desires’ or ‘sense of well-being’, quality of life should be a central concern in clinical practice and its evaluation a fundamental part of health-care provision.

3.4 Assumptions

For the purposes of this dissertation, quality of life is defined as “an individuals’ perception of their position in life in the context of the culture and the value system in
which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1993, p. 153). “It is a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment” (WHO, 1993, p.153).

Several assumptions underpin the conceptualization of quality of life adhered to in this study. First, quality of life is seen as a multi-dimensional phenomenon. Second, as quality of life arises out of a complex person-environment interaction, a holistic approach is necessary to understand it. Third, quality of life is a dynamic, complex constellation of interacting domains. Thus, it can change for individuals over their lifetimes in terms of some or all of its domains. Fourth, although its components may be relevant across groups of people, the quality of life experienced by individuals will vary from one person to another. Individuals evaluate their quality of life within the framework of their own personal system of beliefs and values. Finally, quality of life is subjective, thus the perspectives of individuals are most important in understanding their quality of life (Renwick & Brown, 1996; Schipper, Clinch & Olweny, 1996).
Chapter 4
Methodology

4.1 Research Approach

Qualitative

Given the limited research in the field of quality of life and pediatric heart transplantation, and the complex nature of the phenomenon under study a qualitative approach was appropriate for this study. Qualitative methods are often used to explore substantive areas about which little is known and can “obtain intricate details about phenomena such as feelings, thought processes and emotions that are difficult to extract or learn about through more conventional research methods” (Strauss & Corbin, 1998, p.11). Inherent philosophical principles include an inductive approach to knowledge building, and the view that there is no single objective reality, but rather that realities are constructed from human perspectives, shared interactions and attributed meanings. The ways in which individuals view their worlds and create meaning from diverse life experiences can best be tapped by a qualitative approach. Qualitative methods enable people to tell their own story about a specific experience in their own words and to explain their feelings, wants and needs from their own perspective. Adopting a qualitative research methodology for this study made it possible to learn how pediatric heart transplant recipients construct their worlds and afforded the opportunity to understand the meaning they ascribe to their transplant experience.
Grounded Theory

To achieve the aims of this qualitative study, a grounded theory approach was implemented. Grounded theory methodology falls within the tradition of qualitative inquiry (Creswell, 1998), and was developed to capture the meanings of experiences (Charmaz, 2006). It was first articulated by Glaser and Strauss in 1967 and has since continued to be refined. Grounded theory methods are often used in areas of inquiry where theory is sparse or underdeveloped and is a robust and well-tested methodology in the investigation of health phenomena (Charmaz, 1990, Thomas & James, 2006, Woodgate, 1998). The grounded theory method provides a set of useful strategies or guidelines for gathering and analyzing qualitative data with the intent to construct theories ‘grounded’ in the actual data (Charmaz, 2006). The generation of a ‘grounded theory’ or theoretical understanding of a particular phenomenon or lived experience is the centerpiece of grounded theory research (Creswell, 1998; Strauss & Corbin, 1998). The distinct lack of theoretical research in the area of quality of life following pediatric heart transplantation and the subjectivity of the inherent issues of the transplant recipient’s experiences warranted a method of inquiry that could effectively synthesize the subjective experiential data to generate theoretical propositions and formulate hypotheses for further study.

Epistemological Orientation

This grounded theory study was framed within a social constructivist epistemology. The goal of a social constructivist is to understand the complex world of lived experience from the perspective of those who live it. A social constructivist values the firsthand
knowledge of participants whose life experiences are being studied and attends carefully to the details, complexity and situated meanings of their everyday world (Charmaz, 2006). Proponents of this philosophical persuasion believe that the world of lived reality and situation-specific meanings are constructed through prolonged, complex processes of social interaction (Schwandt, 1998). They assume that individuals create and maintain meaningful worlds through dialectical and other social processes by which they interpret their world and act within it (Charmaz, 2000). Social constructivists turn their attention toward shared constructions of meaning and knowledge (Schwandt, 1998).

This epistemological perspective has implications for the inquiry process. A social constructivist perspective assumes the researcher to be an active observer who engages with participants in a close and interactive manner (Charmaz, 1990). Both data and analyses are seen as social constructions created from shared experiences and relationships with study participants (Charmaz, 2006). “Research participants’ implicit meanings, experiential views – and researchers’ finished grounded theories – are constructions of reality. Any theoretical rendering offers an interpretative portrayal of the studied world, not an exact picture of it…and it is contextually positioned in time, place, culture and situation.” (Charmaz, 2006, p.10)

Given the integral role of the researcher within the research process, it is essential that they identify and acknowledge their own biases and values (Janesick, 2000). Researchers bring to their studies the general perspectives of their disciplines, their own philosophical, theoretical and methodological propensities, their particular research interests and their
biographies (Charmaz, 1990). In a social constructivist approach to grounded theory, researchers must become aware of their biases and values, and actively reflect on how these might shape both the research process and product. This practice of uncovering the assumptions and biases of the researcher has been referred to as a ‘cultural review’ or ‘reflexivity’, and was undertaken by the researcher for this program of research (McCracken, 1988). In particular, it was important for the researcher to recognize personal and professional factors that might have had a bearing on the research process, including the researcher’s familiarity and clinical experience with the study population.

4.2 Research Design

Ethical Considerations

This research was reviewed and approved by the Hospital for Sick Children Research Ethics Board and the University of Toronto Health Sciences I Research Ethics Board. Consistent with research ethics, appropriate measures were taken to ensure the security and confidentiality of personal health information and research data, including participants’ names coded, records and computers secured and research data access limited to the research team. Informed written consent or assent was obtained from all study participants. (Please see Appendix A for a copy of the Consent/Assent Forms)

While the study posed no physical risks or harms for participants, the content of discussion in interviews had the potential to elicit upsetting issues. To maximize safety for participants and minimize any negative effects, a social worker was available to
provide psychosocial support as desired by participants. However, this resource was ultimately not required in the study.

Sample

Participants for the study were recruited from the Heart Transplant Program at the Hospital for Sick Children in Toronto, Canada. The Hospital for Sick Children is one of the largest pediatric academic health sciences centres, with an international reputation for excellence in research and training. The Heart Transplant Program was started in 1989 and is presently one of the largest pediatric heart transplant programs in the world, with patients and families referred from all parts of Canada. By the spring of 2009, 419 patients had been assessed for heart transplant, 346 had been listed, and a total of 235 transplants had been performed in 219 children (14 children received 2 transplants and 2 children received 3 transplants). Of the 219 children transplanted, there are 167 survivors (A. Dipchand, personal communication, June 1, 2009). The age of recipients ranges from 4 hours to 19 years. Approximately 16-20 transplants are performed every year by the Heart Transplant Program and patient care is provided by a multi-disciplinary team of pediatric transplant cardiologists, transplant nursing specialists, social workers, dietitians, occupational and physical therapists, pharmacists, adolescent medicine specialists and psychologists.

All heart transplant recipients between the ages of 12 – 17 years (n = 31) who were able to participate in open-ended interviews were invited to take part in the study. It was assessed that only two patients could not participate due to developmental delay. Thus
the sample was essentially the entire population of patients in this age cohort. The age of 17 years was chosen as the upper age limit, as this is typically the upper age of childhood and is also the age when patients transition from care at the Hospital for Sick Children to an adult care facility. Based on qualitative grounded theory guidelines a sample of 25 – 30 participants is recommended to provide concurring and confirming data, and to ensure saturation (Strauss & Corbin, 1998).

Theoretical sampling, a hallmark of grounded theory studies, typically guides recruitment. As themes and working hypotheses begin to emerge, participants are selectively recruited two or three at a time according to theoretical sampling techniques. In this study, the researcher initially sought participants who had in-depth experiences that helped illuminate the breadth of the group’s experiences and later the interconnections among factors and events that underpinned those experiences. However, as the study evolved and potential participants became aware of the study, almost all adolescents in this small population wanted to participate. Accordingly, minimal over sampling seemed to occur as new themes did not appear after approximately twenty participants. However, the additional participants corroborated findings and added descriptive richness to emergent themes.

The criteria for eligibility included heart transplant recipients between the ages of 12 – 17 years who spoke English and were a minimum of three months post-transplant. Exclusion criteria comprised heart transplant recipients who were not able to participate in qualitative interviewing due to developmental and/or cognitively delay, as evaluated
by the most responsible health-provider or designate. Also, adolescents were excluded if, in the judgment of the responsible physician or social worker, participation would present undue hardship and/or emotional distress.

A health-care professional on the Heart Transplant Program, who was known to the patients and families, made initial contact with prospective participants by mail (See Appendix C for a copy of the Information Letter). The letter included an introduction and description of the purpose of the study, potential risks and benefits, and acceptance of study participation. Those heart transplant recipients who were interested in participating were asked to contact the principal investigator to indicate their willingness in becoming a study participant. One follow-up phone call was made to inquire if potential participants had any questions and if they were interested in participating. If prospective participants were interested, they were contacted by the principal investigator to complete consent forms.

**Data Collection**

Data collection procedures were designed with great care, taking into consideration the need to develop depth and breadth of data while limiting the potential burden on young participants. To ensure an in-depth understanding of participants’ perspectives on quality of life following pediatric heart transplantation, open-ended exploration of recipients’ experiences included semi-structured interviews and health-care database reviews.

(1) **Semi-Structured Interviews:** As an instrument of inquiry, the qualitative interview proves to be powerful and illuminating. The qualitative research interview is
an interpersonal situation which enables knowledge to evolve or be constructed through human interaction (Kvale, 1996). The interview represents a directed conversation whose purpose has been depicted as “the description and interpretation of themes in the subjects’ lived world” (Kvale, 1996, p.137). This qualitative method is ideal for gathering experiential data that can reveal participants’ views, feelings, intentions and actions, as well as the contexts and structures of their lives (Charmaz, 2006).

Open-ended interviews were conducted and were guided by a semi-structured, developmentally appropriate interview guide. (Please see Appendix B for a copy of the initial interview guide). The development of the interview guide was based on the clinical experience of the researcher and thesis supervisory committee, as well as available literature. Although an interview guide was developed, the open-ended interviewing technique assumes that perceptions and meanings cannot and should not be standardized (Denzin, 1989). The phasing of the questions and the order in which they were asked varied for each individual. The interview guide was not used to force a preconceived framework onto the interviews but rather to assist in eliciting participants’ description of and reflection on their experience (Charmaz, 2006). The interview guide included questions that were broad and open-ended, as well as prompts to assist the researcher to elicit detail. Consistent with grounded theory methodology, the interview guide was revised as needed, following the first few interviews and throughout subsequent data collection. Through this revision process, emergent themes were pursued and explored in further detail and depth.
On-going interviews served to saturate categories and simultaneously to begin to test emerging theoretical ideas. Establishing theoretical saturation, that is reaching “the point in category development at which no new properties, dimensions, or relationships emerge during analysis” (p.143), is an essential component of grounded theory designs (Strauss & Corbin, 1998). Therefore, participants continued to be recruited and interviewed to ensure the validity of the emerging theory and to prevent premature closure.

Data collection took place between the period of July 2006 and April 2008. Face-to-face interviews were conducted on a one-on-one basis by the researcher at a mutually convenient location. Adolescents were given the choice of where they wanted to be interviewed in order to help in the development of rapport and trust between the researcher and participants. All adolescents preferred to be interviewed in the health-care facility, either in an outpatient clinic room or in the researcher’s office. During the interviews, establishing a trusting relationship was critical. Therefore, the following strategies were undertaken: (1) ensuring participants were aware that they could stop the interview at any point, (2) ensuring that participants did not feel that the interview process was a test, (3) not placing demands on participants to respond in a particular way, (4) allowing participants as much time as they desired in responding to questions, and (5) ensuring there were no feelings of disapproval on the part of the researcher (Ross & Ross, 1984). All interviews were recorded on audiotape in order to preserve their authenticity and fieldnotes were made during all interviews. Consistent with research ethics requirements, appropriate measures were taken to ensure participant confidentiality. The
interviews were approximately one hour in length (ranging from eighteen minutes to two hours and twenty-two minutes), dependent upon participants’ ages and responses.

(2) Health-Care Database Reviews - In order to understand the variety of illness trajectories and treatments of participants, relevant patient data were collected from the Heart Transplant computer database. Transplant and medical background were obtained for all participants for inclusion in analyses. Variables collected include: demographic information, underlying diagnosis, time on wait-list, pre-transplant medical status, time post-transplant, treatment regimen and medication profile, morbidity issues, days in hospital and number of clinic visits over the previous year.

Data Analysis

Following verbatim transcriptions of the interviews, transcripts were subjected to qualitative data analysis, assisted by a qualitative computer software program for data management (N-Vivo). In using a grounded theory approach, data collection and analysis occurred simultaneously. Theory evolved through continuous interplay between data collection and analysis. The central feature of this analytic approach involved constant comparative analysis and included a system of multi-stage coding: (1) open coding involved line-by-line review of text linking notable key passages to illustrative phrase or codes, (2) axial coding involved systematically reviewing the open coding in light of the research objectives, and clustering codes into larger, conceptually-related clusters so that there was a coherent summary and picture of the data, and (3) selective
Coding involved identifying cases that illustrated the themes and those that offered a contrasting view. This process is important for the final development of working hypotheses and negative case analysis. Asking questions and making memos related to code notes and data comparisons were part of the process of coding.

The analysis process began with the linking of codes to help summarize the large amount of raw textual data. As data collection continued, analysis began to focus on the potential linkages among codes allowing a preliminary picture to be developed and tested through subsequent interviews. Consistent with the constant comparison method, as new patterns or themes emerged, earlier data were revisited to ensure that coding was in accordance with these later themes and to understand variation of patterns across the dataset. Lastly, codes were reassembled in order to map the theorized linkages and interconnections among the various codes or clusters, and represented in a schematic form. Emerging patterns, themes and theoretical constructs were scrutinized, based on multiple (3 researchers) independent blind reviews of transcribed interviews, to ensure inter-rater reliability. Data analysis concluded when the category development was dense and the relationships between categories were well-established (Creswell, 1998). The research culminated in a ‘grounded theory’, or an abstract theoretical understanding of the ‘lived experience’ of pediatric heart transplant recipients. Ultimately, an explanatory, inductively derived theory emerged of factors that influence the experiences of pediatric heart transplant recipients with respect to their quality of life.
4.3 Quality Criteria

Trustworthiness

Trustworthiness criteria serve to enhance the rigour of qualitative research.

Trustworthiness is sought to verify that the findings of a study are authentic and grounded in reality (Lincoln & Guba, 1985). The design of this grounded theory study took into account current recommendations for ensuring quality and trustworthiness in qualitative methods (Erlandson, Harris, Skipper & Allen, 1993; Padgett, 2008). The following measures for enhancing rigour and trustworthiness were incorporated into the design of this study:

*Prolonged Engagement* – The in-depth interviews provided sufficient immersion into the lives of participants and permitted engagement with participants’ perspectives. Moreover, in addition to conducting a thorough literature review, the researcher has been working in the field of pediatric transplantation for over ten years, and the thesis committee has substantial experience in the child health-care field.

*Triangulation* – A variety of sources of information, in this instance interviews, fieldnotes and health-care database reviews, provided context and justification for emerging themes. An interdisciplinary thesis supervisory committee informed the study development and data analysis, and multiple coders ensured that the categories and themes that emerged were confirmed by inter-coder consensus.

*Peer Debriefing* – Regular supervisory meetings were held where ideas and possible preconceived notions and potential alternative explanations were explored. In addition, a peer support group of inter-professional colleagues met on a regular basis and served as a mechanism for peer debriefing.
Member-checking – At the conclusion of each interview a brief summation of the material was presented to the interviewee. All participants had the opportunity to review and comment on their transcripts, as well as on emerging research findings. Participants verified that the interpretations and theory development were grounded in the data and resonated with their ‘lived experience’. While not all participants experienced each emerging theme within their own reality, they agreed that all themes were potentially relevant or realistic among the pediatric transplant population.

Negative case analysis - Disconfirming or inconsistent cases relative to an emerging phenomenon, theme or theoretical observation were sought.

Audit Trail – Minutes for all supervisory meetings, audio taped interviews, interview transcripts, fieldnotes, memos and a reflexive journal noting decisions made during data collection, coding and analysis were collected.

Referential Adequacy – Generated themes include rich descriptive accounts and quotes that present contexts and circumstances of sampled participants, findings and interpretations. Data from health-care database reviews, in addition to the interviews, provide background and support analysis and interpretation.

Through the multiple strategies described above, trustworthiness was demonstrated. Based on this establishment of trustworthiness, it is presumed that the study findings contribute to an enhanced understanding of the phenomenon and illuminate the realities and experiences of study participants (Lincoln & Guba, 1985).
Authenticity

It is argued trustworthiness may not be sufficient as a measure of quality and rigour in qualitative research. While trustworthiness addresses methodological soundness, the criterion of authenticity adds elements of fairness and reciprocity in the research process, as outlined below (Erlandson et al., 1993; Lincoln, 1995):

*Ontological and Educative Authenticity* – Testimony of participants confirmed that valuable benefits were gained by sharing their ‘lived experience’ and an enhanced understanding was obtained surrounding the nature of the reality of life following pediatric heart transplantation. Participants’ knowledge and appreciation of the perceptions and experiences of others were expanded and they appeared to become more equipped in constructively managing and living with their health condition.

*Catalytic and Tactical Authenticity* – Participants testified they experienced an enhanced sense of empowerment throughout the research process and were stimulated to take action. There was a willingness to engage actively in further educational, clinical and research endeavors to enhance the experiences and reality of this unique population.

In sum, through the multiple procedures described above, trustworthiness and authenticity were demonstrated. Based on this establishment of trustworthiness and authenticity, it is presumed that this research illuminates the ‘lived experiences’ of participants.
5.1 Participants

Twenty-seven heart transplant recipients from the Heart Transplant Program at the Hospital for Sick Children participated in the study, out of a total of 31 recipients who were eligible, representing a response rate of 87%. Of these 27 participants, 18 were female (67% of sample), the median age was 15.5 years (with a range of 12.2 – 18.4 years), and the median time post-transplant was 3.2 yrs (with a range 0.3-11.1 yrs). Seventeen of the participants had an underlying diagnosis of acquired heart disease, and ten had a congenital diagnosis. Twenty-one of the participants had undergone one heart transplant, and six had undergone two or more heart transplants.

The sample was geographically diverse. Participants lived in various regions across Canada with a mean distance from SickKids of 933 kilometers (20 – 4344 kms). Of the 27 participants, the permanent residence of seven participants was outside the province of Ontario and a total of eighteen had to relocate to Toronto temporarily. Seventeen participants were in dual-parent households, and ten participants resided in single-parent households. All except one participant had one or more siblings. Participants came from diverse ethnic and racial backgrounds (e.g. English and French Canadian, Asian, European, African, East Indian). Annual family income ranged from under $20,000 to more than $100,000, with a mean income in the range of $52,000. Many children spoke more than one language but English was most commonly used.
5.2 Findings

The findings illuminate adolescent heart transplant recipients as profoundly affected by their transplantation experience. Participants described a range of experiences and processes that occurred over the course of their transplant journey. They spoke about various biopsychosocial phenomena associated with transplant. The findings appeared to reflect the temporality of the transplant experience; with experiential data related to quality of life and transplantation being clustered and presented along notions of temporality, including (1) the pre-transplant experience, (2) the transplant surgery and hospitalization, and (3) the post-transplant experience.

The data produced a rich set of interrelated concepts, categories and themes. The three key categories that emerged from the data are presented below, along with emergent themes and supporting quotes from participants. The ensuing verbatim quotes illustrate some of the ideas participants expressed about their experiences of life following transplant. The notation ‘…’ within a quote indicates missing words. The use of brackets indicates a word inserted by the author to convey better the meaning of the transcribed quote. While some quotes that have been included are not necessarily descriptively rich, the findings across participants were noticeably similar, supporting saturation and depth.
1) Experiences of Participants Prior to Transplantation – A “Struggle”

to Survive

The pre-transplant experience of nearly all of the participants was characterized as a period of immense struggle within virtually all domains (e.g. physical functioning, social and emotional functioning, academic performance) of their everyday life. They were clearly fighting for survival, with their ability to participate in the activities of daily living rapidly deteriorating. The participants were essentially debilitated by their underlying heart disease. Notions of ‘paralysis’, ‘burden’, and ‘demise’ and other powerful words attributed to their failing health rendered them a vulnerable population pre-transplant.

When discussing pre-transplant experiences, the participants described life as “pretty bad”, “horrible”, “painful”, “really hard” and “such a struggle”. They stated that their quality of life was “really down”, “worse” and “not half as good as it is now”. Before undergoing transplant, the participants recalled feeling unwell: “I just remember being really, really sick”, “I would get sick a lot”, “I was always sick”. In addition, they acknowledged their deteriorating health: “I was getting worse and worse” and “my condition was gradually worsening”. Some participants described memories of how close they possibly came to dying: “I was so sick that I worried that I might die”, “I was scared of dying”, “I wasn’t sure if I was going to live much longer” and “I just felt like I was going to die”. They spoke about their frequent hospitalizations: “I was always having to be in the Intensive Care Unit” and “I was in the Emergency a lot”.
Physical Limitations

Prior to transplantation, the participants experienced significant physical limitations, with many expressing this clearly: “I didn’t even walk that much”, “I couldn’t walk anywhere really” and “I couldn’t get up and play, run around”. The participants had difficulty mobilizing or engaging in activities of daily living. One participant noted: “I couldn’t walk for long. I was out of breath doing it. Everyone had to carry me”; another stated: “I couldn’t get up and couldn’t walk from one end of the road to another without being out of breath. If I walked for ten minutes I’d be out of breath.” Another participant reported “I had a bunk bed and when climbing up the ladder I was out of breath. When I got up, I collapsed”. Almost all participants shared memories reflecting severe physical debilitation: “I couldn’t really do anything basically”, “Before the transplant I couldn’t really do that much. I couldn’t do that much at all” and “I remember not being able to do a bunch of things”. The significant decrease in physical functioning essentially paralyzed the participants’ lives: “I was too sick to do anything really. I would just like sit on the couch and not play or anything”, “I wouldn’t want to go outside or go anywhere” and “Before (transplant) I was just lying in bed”. The participants related stories about the restrictions on their social and recreational activities prior to transplant: “I remember ...I couldn’t swim very good. It was hard for me to run and play like my cousins. I couldn’t run and do all that.”, “I couldn’t do the stuff I can do now. I couldn’t play hockey, couldn’t play volleyball. I used to get beat out really easily.”, “I just couldn’t play them (sports). I didn’t have the breath to do them.” and “I wasn’t allowed to dirt-bike anymore, I wasn’t allowed to play sports because I had issues of possibly
having a heart attack”. As noted by these quotes, participants’ memories of the pre-transplant experience reflected restrictions in choice and activities, and feeling unwell.

Lethargy

The participants discussed feeling weak and vulnerable prior to transplant. They conveyed statements such as: “I was really weak”, “As soon as I got up I felt off balance”, “It feels like when you have it, an abnormal heart, like you don’t want to do anything, you just lie there and you don’t want to get up because you’re weak” and “I would get out of breath, or get hurt easier than other people”. A few participants talked about always feeling cold prior to transplant: “I was usually really cold”, “I remember being cold” and “I was really cold”. Most participants recalled suffering from chronic fatigue which was often incapacitating: “I had such low energy and just getting up and stuff. And getting up four steps on my front porch was a hassle and made me pant and out of breath, and I was always tired and it was that much harder.”, “I was always short of breath”, “…always being fatigued and not able to lift things and push doors that were heavy”, “I was usually tired all the time”, “I couldn’t even move my legs because I was so tired”, “I didn’t have any energy”, “I was very tired and exhausted”, “With my old heart I was more tired and less active because I had less energy” and “Before transplant my energy was really low”.

Social Isolation

Before transplant, the participants often felt socially isolated with a limited circle of friends due to poor health and physical limitations. They stated “I was treated more
fragile (when playing with friends)

“I couldn’t keep up with my friends”, “If I was with my friends going for a walk or something, I would have to take a break”, “They (friends) would usually like play tag and all that. I was just like, ‘I can’t do that’.” and “I didn’t feel like a regular kid”.

Some participants expressed concern and fear around rejection by peers due to perceived differences related to physical functioning. One noted: “I couldn’t do things with my friends, I was usually left behind. I didn’t have many friends because nobody wanted to wait for me; like an hour to walk up the street.”; while another stated: “I remember when I was always telling my friends to stop because I needed a break and it used to make me feel like I was sulking too much and I felt they would get annoyed with me soon. So I would worry about that.”

Discomfort with Physical Appearance

The participants described physical conditions caused by their heart disease which negatively affected their appearance prior to transplantation. Many recalled: “I always had blue lips”, “Before transplant my nails were always blue because I didn’t have enough oxygen going through my body”, “I was always pale and I always had bags under my eyes and I always looked tired”, “I was always puffed up because of the liquid”, “I was always pale. My eyes were always...coming down. Droopy.” and “I used to be blue-ish.” There was an awareness of difference and an underlying sentiment of self-consciousness. Participants also commented on their decreased appetite: “I didn’t eat all that much”, “I couldn’t even eat. My brother tried to give me a Caramilk and I couldn’t even eat it. And I love chocolate.”, “I would not eat because I just didn’t feel like it. I was getting tired lifting a fork or a spoon”; as well as abdominal pain: “Like,
“your stomach was upset or I had heartburn” and “I’d have really bad stomach pains and I would be crying. I couldn’t do anything, just sit there and bawl.”

**Tough Making the Grade**

Before undergoing transplant, the participants acknowledged their absenteeism from school: “I still went to school even though I missed a lot because every two weeks I was in the emergency again, but I still went even though it was hard”, “I’ve missed a lot of school. I missed, um, at the end of grade 3 I was sick, same as grade 4. I missed a lot. So between that, if you add them all up...it’s been a lot.”, “I missed a lot” and “Sometimes I didn’t go to school because I didn’t feel good and I was tired. I missed a lot of school. I didn’t like that.” A few participants noted their inability to get to school: “I remember walking to school and it was very hard, and it wasn’t even a far walk, and I was just tired. I started staying home from school.”; and others reported difficulty navigating within the school: “It was hard at school, the stairs” and “There were a lot of stairs and stuff and I was always about 10 minutes late for class even though my class was only a 2 minute walk away.” Many were unable to participate in gym and recess due to decreased physical functioning: “There used to be some stuff I couldn’t do, like gym stuff. I could if I wanted to, but not for very long. So I used to sit out.”, “I had stopped going to gym”, “My peers were, in recess they would play tag or they would skip rope or something and I couldn’t do all of those things” and “I couldn’t do track, I couldn’t do sports and I couldn’t really do recess.”
2) Experiences of Participants at the Time of Transplantation – A Difficult Transition

Many participants vividly recalled the moment in which they first learned that an organ had become available and their reaction to the news was wide ranging from “scared”, “anxious”, “so nervous” to “shocked”, “numbing”, “surprised” to “so excited” and “happy”. The range of emotions suggest the potential of a multilayered response including both (and simultaneous) positive and negative thoughts and feelings when offered a heart. The call that a donor organ had become available set the wheels in motion for an arduous trek from transplant to recovery. The actual transplantation signified a remarkable transitional progression for all participants that was described as “difficult getting through” and a “tough road”.

Hospitalization and Treatment Protocol

Following the transplant surgery, participants viewed the hospitalization experience as a demanding phase that marked a significant process of change. Participants described the immediate period of recovery following the surgery as difficult and painful. They had vivid memories of the immense challenges they faced trying mobilize themselves: “It’s tough what you’re going through it…it’s hard after...when you’re first getting up and trying to walk again”, “It was tough to get through...I had to learn how to walk again. It was very painful.”, “It hurt a lot. I couldn’t really stand up straight because my scar was still healing. It was scabby. I kind of had to hunch down and walk.”, “I had to re-learn how to walk. It was not fun at all.” and “It was hard getting out of bed. I had so much fluid still. It was hard to move.”
Almost all participants referred to specific aspects of the treatment protocol which they recalled as painful or at times frightening. Most participants spoke fervently about their aversion to biopsies: “The worst thing is the biopsies. That is the worst thing, because they keep you awake during it, unless they changed it.”, “The biopsies sucked”, “I just hated that mask (for biopsy). The mask freaked me out. I didn’t like it. I’m not claustrophobic; I just don’t like the mask over my head.”, “The biopsy (is the worst). I hate having a sore neck afterwards.”, “Biopsy is the worst. I don’t like them.” and “Having the procedure (biopsy)...it’s not painful, but you feel a lot of pressure on your neck. It hurts a little.” Many participants also noted their displeasure with the medication regimen, in particular the higher doses immediately post-transplant and the medication prednisone: “Some stuff that I don’t like about the heart transplant. You have to take medication every day and it gets kind of tiring.”, “I don’t like the pills. But I don’t like liquid medication. Most of the medication tastes really bad. It’s hard to take them. You have to get the right juice, flavoured juice.”, “There was this medication prednisone that tastes yucky...and it makes you feel swollen”, “I felt all fat and it felt weird (being on Prednisone). I was more swollen around the knees and the face and everywhere.”, and “The prednisone, I really hated that medication...When it starts to kick in I was eating so much and my face was puffy...I don’t know, it’s just a weird thing, I was never full. My stomach was always bloated, I felt like a bag of sand, but I would still want to eat a bunch of stuff, I was gross.”
Grappling to incorporate a new heart as part of identity: “You realize you have someone else’s heart”

At least half of the participants spoke about the emotional impediments they faced as they struggled to adjust to the presence of a foreign organ that had been retrieved from an anonymous person who had died. Many participants shared: “It’s just an organ. It’s from another person; that sort of freaked me out. And because I’m small it would be a child.”, “You realize that you have someone else’s heart. And it’s kind of weird at first. How can I have someone else’s heart, how can that work?”, “It’s kind of weird in a way, but I got used to it. I was irked by it; I didn’t realize that someone else’s heart was inside of me.”, “Wow, I have someone else’s heart inside of me”, “It felt a little weird, but then okay”, “It’s kind of, it’s weird in a way. It’s like, um, you’re still alive, but not with your heart.”, “A lot of people joke about it, ‘you have his heart forever’, it’s a really weird feeling, you think about it, you don’t have your original heart anymore, you have someone else’s heart” and “Sometimes, you think, ‘oh my god, I’ve got someone else’s heart who died.’”. While almost all participants noted that they felt they had successfully adjusted to the idea of incorporating a new organ into their identity, a few participants noted that they still struggled with the idea: “I still feel weird by having someone else’s heart in me. Yeah, that is the only part of me that is different right now.”, and “I’m still kind of grossed out because I got a boy’s heart, but at least I’m alive.” A handful of participants also wondered about the idea of developing characteristics or personality traits of the donor, noting: “I remember before I got my heart transplant, I was thinking, I wonder if, I get anything that they had. I don’t think that is true or anything though.”, “Just thought maybe that I’d act
differently, but I don’t really act different than before”, “At first... I wondered, if I have someone else’s heart and they liked swimming, and I didn’t like swimming, would I all of a sudden like swimming. I did think that at first” and “I knew that I had someone’s heart and I thought that, um, I didn’t act like myself, I was someone else because I had a new heart so I thought I was that girl. Not the girl on the outside, but the inside. I didn’t want to be like that.”

For some participants the process of adaptation often included a variety of feelings, in particular there were often periods of sadness and guilt: “I know it came from a person that died, that makes me feel sad. I’m happy that I got to live, but someone else had to die for me to live, so it’s a good thing and a bad thing how their family must feel.”, “It’s like ‘wow’, it’s kind of amazing, but then you think of the other person, and it’s like, kind of sad in a way. This other person that you’re living with their heart, they are dead. Because of them, you’re alive. It’s kind of sad”, “I was kind of feeling guilty because someone else’s child had to die for me to live. That bothered me a lot.”, “Like a child had to die for me to get an organ”, and “I still feel guilty and I, well I don’t feel guilty, but I feel sad. I have kind of realized that the person didn’t die for me; wasn’t forced to be killed or anything, just died randomly. And it was his or her choice, because if they didn’t sign up as a donor than that wouldn’t have happened. So they wanted to do it.” When asked if they thought about the organ donor, many participants reported: “Yeah. Often”, “Yeah, every night”, “I always do. You never forget.”, “A lot actually” and “Yeah, when I’m going to bed.” In one case the interviewer stated, “I’ll use a 0 to 10 scale. So 0 is you never think of the donor, and 10 you think of them all
the time. Where would you be? The child replied, “10”. Several participants noted that they were curious about their donor and had numerous questions that, if given the opportunity, they would want answered. Issues and questions were as follows: “I do wonder...what the person was like, what they liked to do and stuff”, “Um, how they died, what happened, just about family”, “I wondered like, what had happened to him...was it in a car accident, or something like that. I wondered like where the family was, why they would give up their son’s heart.”, “Who I got it from. And why did they give it to me?”, “I wanted to know...what happened to that person”, “I always wonder what the person was like, what their name was, how they were, what they liked, what they were good at”, “I wonder if it’s a girl or a boy, stuff like that”, “where it (the heart) came from and if it was a boy or a girl” and “How the person was, how old? male or female? Where they are from? How they died?”

Difficulty Returning to School

Some participants commented on the difficulties they faced when transitioning back to school. They spoke about the disruption of the transplant experience on their school attendance and its impact on their academic functioning. One participant noted: “They (school mates) were like, ‘you’re back, yeah’. They were so happy, but it was kind of hard to try and catch up to everything.”; another mentioned: “I have gaps in my learning. I consider myself smart, not to sound conceited, but I do. I have gaps in my learning. I have never learned division for example.” and a third stated: “In a way, with school it was disruptive. I had to catch up a lot when I got back. I did catch up, I managed to do that.” A couple of participants expressed the difficulties encountered
when needing to repeat a grade: “Because I had a heart transplant and I had to miss school, I had to repeat grade...I didn’t like it. I didn’t have my friends there with me. I had to make all new friends. It was hard.” and “I was the oldest person there and all my friends were at a different school. It was difficult.”

Practically all participants reported that bullying was a common occurrence within their school and they seemed to accept it as a ‘fact of life’. A handful of participants however appeared to be the targeted victims of bullying immediately following transplantation, yet this diminished over time. One participant stated: “It was actually quite difficult for me (returning to school). Because of the prednisone and the other rejection medications, I retained water. And I was quite big. And because of that, because it was such a drastic change, when I came back the students bullied me and they called me names, and it was quite bad.”; another noted: “Because of the heart transplant they were saying, ‘this girl had 2 heart transplants and she thinks she is so special.’ They are thinking that I am a freak, and jealous.” A couple of participants spoke about particular verbal assaults pertaining to their newly acquired organ: “When I got back it was just like, they were acting like I was different and all that and someone said that my heart wasn’t a person’s heart, so then I got teased about that. I think it seems weird that people think I’m weird if they know. That is why I don’t like telling people.”, “I got bullied a lot after transplant when I went home. People used to say, ‘you have a monkey heart’. And I know I got bullied a lot. That was hard, but after I went to high school the bullying stopped and I got through that.” and “I was walking home one day and this girl, um, she was like, ‘a whole bunch of people in school are
saying that you have an animal’s heart’, and I’m like, ‘no’. And she’s like, ‘are you
sure, everyone is saying that.’ And I was like, ‘no’. And I got home and I was bawling
my eyes out.” While this level of bullying was particularly intense for a few
participants, the passage of time eased these negative experiences.

3) Experiences of Participants Following Transplantation - An
Awakening and Transformation

Participants commonly depicted their lives in positive terms, such as “pretty good”,
“great”, “awesome” and “fun”, and appear to be leading satisfying lives. Many of their
comments were comparative in nature to their life pre-transplant: “Now it’s a lot better
for me”, “Life’s been better, after the heart transplant”, “I feel happier”, “Life is so
much more vibrant. So much easier.” and “once you get it (transplant); life gets way
better”. When asked to describe their “quality of life”, participants noted it was “good”,
“excellent” and “fantastic”.

Movement toward Normalcy

Despite the extraordinary experience of heart transplant, the participants worked to
minimize the negative impact of transplant and made comments such as: “It’s not
really that bad”, “It’s a big thing, but it’s not that big”, “Everything has been great”,
“There is nothing to be scared of”, “Everything was perfect” and “I only remember
good things that happened.” The participants spoke about the importance of being able
to live a normal life. For the participants, routines of post-transplant life became very
ordinary. The follow-up medical regimen was treated as commonplace and was discussed factually. The participants attempted to fit the experience of transplant into their ordinary lives by normalizing it, stating: “I make it seem normal. I don’t make it seem like I have a medical problem at all”, “Life is pretty much normal, except for the gross pills”, “It feels like my life is just like it was before except that I have to take medication” and “After (transplant) you’ll find it the same going back to normal and it’s like you never had it. You take the meds…it’s like your life is totally normal.”

Most participants felt they were just like any one of their peers and they did not think they were treated differently. They felt they led a “normal” life: “I feel normal”, “You live a normal life; it’s not like you can’t do certain things”, “I consider myself pretty normal”, “You can lead a very normal life. It’s amazing how normal life can be.” and compared themselves to “regular” healthy children: “It (life) is like normal, like everybody else”, “I get to be a regular kid”, “It’s (life) no different than anyone else”, “I think I’m just like other kids that didn’t have a heart transplant” and “I would say that you’re not that different. The only thing that is different is that you take medication, but you’re not really that different from the others.”

Overall, the participants saw themselves as healthy. All reported improvement in their well-being and a release from the burden of their chronic illness. The participants echoed statements such as: “you’re surviving and you’re breathing and you’re not feeling that much pain anymore”, “I’m physically better”, “I feel so much better than anything at all”, “Better by not feeling any pain”, “You feel a lot better, you’re not
feeling weak and sick”, “I feel more healthy than I did before” and “…being able to have a normal heart and not having to go to the hospital so much.”

Satisfaction with Appearance and Wellness

Beyond initial responses post-operatively, the participants later described a greater satisfaction with their body image. Many reported positive changes in their physical appearance and perceptions of self: “I remember that I walked into the washroom in the hospital, I asked my aunt if she put lipstick on me and my lips were red because I was used to seeing them blue”, “Before (transplant) my nails were always blue because I didn’t have enough oxygen going through my body. They are red now.”, “My colour is better. I’m not as pale.”, “No one stares at me anymore...because (pre-transplant) I had purple lips and purple hands”. Some participants also noted improvement in their appetite: “You have a better appetite”, “I just feel better with eating now” and “I can eat a lot more. I eat a lot now.”

Superior Physical Functioning: “I can do everything”

The participants expressed excitement about the enormous improvement in their physical functioning. Post-transplant, they consistently conveyed a positive attitude about their own abilities and were discovering a new way of life. A sense of optimism and an ability and confidence to “conquer all” was reported. One participant noted: “I can do everything”; while another stated: “I can pretty much do anything now if I want to.” They were able, often for the first time, to enjoy a full range of activities without significant impairment. Numerous participants shared: “I can do more than anything
before”, “I can do a lot more things than I used to be able to do”, “Now it’s easier to
do more stuff”, “I can do more things than before” and “What I used to not be able to
do, I can do now.”

After undergoing transplant, the participants talked about regaining their strength, which enabled them to become more mobile and significantly more active. Participants reported: “My activity level is better”, “One thing that has changed is that I’m more active and stuff” and “Before I used to take the elevator; now I can just run right up the steps.” They also emphasized the improvement in their body’s performance. One participant noted: “Before when I used to run around I’d run for 5 minutes and then I’d sit down and it used to hurt. Now I can run for 10 minutes straight and I won’t take a break even for 5 minutes and it doesn’t hurt.”; and another excitedly shared: “I actually learned how to do a back flip on the ground...with this new heart.” Nearly all participants commented on their energy levels: “I remember when I first woke up; I thought there was a burst of energy. It’s really great.”, “I’m less tired and stuff than I was before”, “Once you wake up (from transplant) you are re-energized”, “I don’t get as cold as easily either. I’m not as tired. I can walk more... I have more energy.”, “I have more energy than I did before the transplant. I sweat now.”, “You’ll be surprised what you notice after it. The energy and stuff. You’ll notice a big difference than before. The energy, and then sweating and stuff.”, “When I got my new heart it was like ‘poof’, energy” and “You feel when you get more energy and stuff, instead of laying in bed, you are excited to get up and go everywhere.”
Following transplant, the participants generally were able to participate fully in age-appropriate activities. Participants focused on the ordinary, everyday tasks that they were now able to accomplish: “You can do all these normal things again, things that you took for granted before and just like, you didn’t realize how great it was. Before it was like ‘oh no, the remote is over there.’ Now it’s just ‘ah’. “, “You can do everyday things. Even being able to go the bathroom, or go upstairs to your bed, anything. Just being able to do that is great.”, “It’s easier to walk and run” and “I can walk up the stairs.” They enjoyed participating with their peers in social and recreational activities and indicated that they were satisfied with their physical functioning. Participants enthusiastically shared: “I know that I can get up every day and I can run and do all that stuff”, “I can do more. I can walk a lot more, and I can swim. I can skate.”, “I feel happier because I get to run and do what I want to do”, “After the transplant I could run, I could play sports. I could do it. I was happy about that.”, “I was really happy because I was able to play again”, “After I had a transplant, I did basketball and cheerleading”, “I did everything. I rode my bike”, “(I could play) a lot more sports than I could before... soccer, volleyball and baseball”, “I can go on longer walks with my dog” and “Climb more trees, run better, think better.” The participants’ comparisons with peer group accomplishments were very favorable, noting: “I can basically do everything that my friends can” or “I can now do the things that my friends do” or “Life’s been better because now I can do the things that my cousins and my brother can do. They used to go biking and I could never do that before, and now I can.”
Enhanced Peer and Family Relations

After transplant, the participants noted that their increased ability to participate in recreational and social activities contributed to more positive interactions with their peers. One participant noted: “I’m able to go out with friends now and not taking those breaks and feeling like I was dragging everyone behind”; and another shared: “I would worry about that (friends getting annoyed with me) and now that has gone away.” They were now able to join their friends in various activities, many noting a ‘sense of belonging’. Participants reported: “I can go and hang out and watch TV with friends and hang out”, “I can stay out (with friends). I’m pretty good with that.”, “Now I just seem to be out every night now (with friends)”, “My friends don’t treat me fragile anymore”, “You can hang out with your friends” and “I have more friends now than I did when I was sick.”

Participants experienced more positive and meaningful relationships with family and friends. The importance of these interpersonal relationships was noted: “I think friends and family are now more important” and “It’s really important. You want to spend as much time with them as you can”. Many participants felt that transplantation had brought them closer to loved ones: “We were close before, but this has made us even closer” and “I think we (family) have a closer relationship now”; and they expressed gratitude for the opportunity to spend time together: “God gave me the chance to see and do stuff with them (family)” and “I think it’s better the way our family is now. We are spending more time together, it seems like a real treasure.”
Integration and Re-energized at School

After undergoing transplant, all of the participants attended school regularly: “It (my life) was like everybody else’s. I went to school.” They were able to enjoy participating with their classmates in school activities, such as playing on the playground, recess and physical education. Participants stated: “I would go to school; I was running and playing with my friends”, “It’s a lot easier to compete with the other people (in gym)”, “Before I couldn’t really participate in gym, and now I can do everything that they can do”, “Before I couldn’t really do gym, but now I can do gym with all of my friends” and “I was on the teams and stuff, that is how I met my friends in school and stuff like that. Like wrestling, baseball, back yard football, I couldn’t do that with my old heart.”

Recognition of Personal Strength and Evolving Personal Resolve

Responses clearly indicated that the transplant experience dramatically impacted the participants’ perspectives on life. After transplant, many of the participants reported feeling different and believed they emerged with a new sense of self. One participant summed it up by stating: “It was almost like a light came on. Like, I’m a whole different person. It’s different, I don’t know. I feel different.” Participants exhibited an increased awareness around their personal strength, and an evolving new personal resolve: “I’m a really strong person for having gone through that”, “I’m really strong...and courageous” and “I find that it’s made me stronger as a person because I went through so much and I had to deal with so much. So I think as a person I’m a lot stronger than I would have been if I wouldn’t have gone through it (transplant).” Participants spoke of resiliency, enhanced coping mechanisms and increased confidence: “(After transplant)
you can cope with things”, “I always try to have faith in myself, in who I am and what I’m capable of doing. I keep telling myself, ‘you are strong, you can do this’. I get motivation to get going again.”, “It’s basically, the best thing is to grow from it (the transplant), and getting stronger from it”, “It’s (transplant) made me a lot more brave and willing to do lots more things than I used to do... now I’m willing to do things, because I know I’ve been through a heart transplant so I’m sure I can do a lot more things than I thought I could do...; just you figure if you can go through a heart transplant, you can do a lot of things.” and “If I like fall down, it doesn’t hurt as much as it used to. If I fell before it used to hurt and I would cry all the time.” There appeared to be a building momentum in advancing one’s sense of having what it takes not “to hurt” or managing to pick oneself up after “fall(ing) down”.

An Appreciation of Life

Participants perceived a change in their outlook on life, expressing a consistently positive perspective and an enhanced appreciation: “I appreciate life more; think about what I’m doing more.”, “…not taking advantage of life. Not worrying anymore what life can have in store for you, what life can be.” and “Now, I see it as an experience doing stuff that I didn’t do before...Before transplant I would just go and go, and go, same thing. Now it just seems like everything, um, each time I wake up I’m sort of thinking ‘oh my, this is just great.’ New day, new things, let’s go and have fun.” Participants spoke about life being more meaningful: “I have more meaning to my life now. I had meaning before, but not as big as this. It made me feel, depending on what relation you have, for me it was God; he wanted me to do something more important. He had more things for me to do.
Someone had bigger plans for me.” and “There is more to life now. Before transplant, I used to like, um, let’s say there is a sculpture outside near a building and I would never notice it and now I’m like ‘oh wow, look at that.’ ... I see more meaning in things. Life seems to have more meaning... It (transplant) has given my life more meaning.”

The participants celebrated life and were immensely grateful for what they viewed as a valuable gift. Examples of this sentiment from the interviews are as follows: “Because I’m alive and not gone. So it’s a good day. Because every day that I wake up is a good day.”, “I’m happy to be alive.”, “Someone has given me a heart and a second chance and I can’t waste it”, “I’m really grateful for it. If it wasn’t for my transplant I probably wouldn’t be here today. And things have been going really great. It’s been great.” and “I have been given this wonderful gift and I have to take care of it. I don’t want to waste what the family gave.” They repeatedly articulated: “Transplant gave me a new beginning” or “A new start on life.” Time after time participants expressed the notion that they had a “second chance at life”, “I know some people see it as a second chance, and that is how I’m seeing it right now”, “Sometimes it’s good to have a transplant because God gives you a second chance at life” and “You know you pretty much got a second chance at life.” Most participants spoke passionately about “trying to live life to the fullest” and “living every day like it’s your last one.”

Positive Attitude towards Transplant: “It’s been good”

The participants consistently had positive attitudes towards their transplant experience and expressed satisfaction with their present life. When posed the question “How do you
explain what it’s like to have a heart transplant to others?” participants responded: “It’s pretty cool. It’s all positive stuff.”, “It’s good in the long run, but it’s kind of a difficult road when you’re doing it”, “It’s worth it in the end, definitely” “It can save you” and “It’s worth it.” A few participants contrasted their experiences with a potential comparator and alternative of death. For instance, one participant stated: “It’s been good. There are some advantages. It’s better than lying down dead and rotting.” Another noted: “The best thing about getting a heart is knowing that you’re still alive and that you don’t have to worry about dying.” Participants also shared advice for other adolescents considering a heart transplant as a treatment option. Comments included: “I would tell them to get a transplant so they could enjoy life better if they have a transplant”, “It will be better in the end”, “It’s a lot happier once it’s done than when you’re going through it. It feels like it’s never going to end, but it is. You’re going to come out of it some day and everything will straighten out.”, “It will be better in the long run. You will be happier unless things go wrong. But it’s definitely better to do.” and “Not to be afraid, it’s all going to get better. I know you’re down having biopsies and it’s a pain and all, but it’s going to get better. Once you get your heart it’s all uphill.”

Participants generally expressed a determination to “focus on the present” and often reported that they “take life one day at a time”. The participants’ responses indicated they did not worry about rejection or never thought about needing another transplant. Nearly all of the participants commented that they “don’t really worry about the future”, with one participant stating “You don’t have to worry about dying.” They had a sense of hope and optimism for the future: “I have high hopes for the future” and “It (the future)
“always turns out good.” Participants demonstrated a positive outlook towards future academic and vocational goals, as well as personal relationships (e.g. boyfriends, girlfriends, marriage, children), “Well before I never wanted to go to college and now I’m thinking that I should.” and “I’m looking forward to having a career, having a family.”

Stories Lived Differently

The three categories: 1) the pre-transplant experience – *struggling to survive*, 2) the transplant surgery and hospitalization – *a difficult transition* and 3) the post-transplant experience – *an awakening and transformation*; and the various themes within these categories, permeated the participants’ transplantation experiences with intense vividness, intensity and consistency. While the above themes were intricately woven throughout the fabric of most participants’ lived experiences, there were three notable exceptions. First, participants who had undergone transplantation as neonates or toddlers (n=4) obviously had no recollection of life prior to transplantation. Some participants relied upon the memories or stories of family and loved ones to capture this period of time. Secondly, participants who had sudden onset of heart failure and were assessed, listed and transplanted within a critically short period of time (n= 6) may have experienced similar aspects of the pre-transplant experience described earlier, but possibly not to the same extreme as those participants living with heart disease over an extended timeframe. Thirdly, co-morbidities did not seem to make a substantial difference in the positive perceptions of participants, except in the case of neuromuscular conditions. Participants who had an underlying diagnosis or condition involving a neuromuscular disorder (n=2)
did report similar post-transplantation experiences but they did not perceive as dramatic a change or improvement in their physical abilities or capabilities.

In summary, participants described a range of experiences which coalesced along the trajectory of time. With few exceptions, difficulties eventually led to increased perceptions of quality of life. A discussion of this temporal and shifting process is addressed in chapter 6.
Chapter 6
Discussion and Conclusion

Despite the establishment of heart transplantation as a life-saving therapy for children and adolescents, little research has focused on the biopsychosocial impact of the transplant process. Few studies have captured the subjective experiences of young heart transplant recipients or have sought to convey these complex experiences in a holistic manner. This program of research addresses this significant gap in knowledge and contributes to enhanced understanding of quality of life following pediatric heart transplantation. In an effort to encapsulate this complex experience and to learn more about the psychosocial issues in pediatric heart transplantation, this research was guided by the overarching question, “What are the experiences and perceptions of pediatric heart transplant recipients with respect to their quality of life?”

By exploring the day to day experiences of pediatric heart transplant recipients, the transplantation experience was captured from the perspective of those who live it and create meaning from it. Adopting a qualitative research methodology for this research made it possible to explore how pediatric heart transplant recipients construct their worlds and the meanings they ascribe to their transplant experience. Twenty-seven adolescent heart transplant recipients from the Hospital for Sick Children participated in this research. These heart transplant recipients generously conveyed their experiences and perceptions of heart transplantation using their own words, means of expression, values and explanations.
6.1 Discussion

The findings from this program of research suggest that the effects of undergoing pediatric heart transplantation are pervasive and substantially impact self-perceived physical, psychological and social well-being. Participants described various profound biopsychosocial phenomena that occurred over the course of their transplant journey. Analysis of the transplant experience yielded themes of quality of life reflecting notions of temporality including: 1) the pre-transplant experience – a struggle to survive, 2) the transplant surgery and hospitalization – a difficult transition and 3) the post-transplant experience – an awakening and transformation. The figure below illustrates a theoretical model that emerged from these findings.

Transplantation - A Transformative Process

<table>
<thead>
<tr>
<th>Pre-Transplant</th>
<th>Time of Transplant</th>
<th>Post-Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Struggle to Survive</td>
<td>A Difficult Transition</td>
<td>An Awakening</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A Transformation</td>
</tr>
<tr>
<td>• Physical Limitations</td>
<td>• Hospitalization</td>
<td>• Improved Self-Perception</td>
</tr>
<tr>
<td>• Lethargy</td>
<td>• Treatment Protocol</td>
<td>• Enhanced Interpersonal</td>
</tr>
<tr>
<td>• Social Isolation</td>
<td>• Assimilation of a New Heart</td>
<td>Relationships</td>
</tr>
<tr>
<td>• Discomfort with Physical Appearance</td>
<td></td>
<td>• Altered Life Philosophy</td>
</tr>
<tr>
<td>• Tough Making the Grade</td>
<td>• Difficulty Returning to School</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A Struggle to Survive

Pre-transplantation emerged as a period of heightened perceived physical weakness, lethargy and vulnerability. Participants’ view of their lives, during this timeframe, before receiving their heart transplant, was framed within a context of debilitation and negative self perceptions related to their health, physical appearance and functioning. During this time, struggling to survive was a primary process and challenge experienced by participants, with a perceived sense of isolation which appeared to be integrated with deteriorating health, chronic fatigue, physical limitations as well as psychoemotional experiences of depression and low self esteem. Lasting memories of life prior to transplantation included adolescents feeling excluded and restricted from participation in a variety of social and recreational activities, alienation and in varying degrees and cases, rejection from peers. These pre-transplant emotions and experiences are echoed in the findings of Lawrence & Fricker (1987), Serrano-Ikkos, Lask & Whitehead (1997), Serrano-Ikkos et al., (1999) and Wray and colleagues (1992, 2007).

A Difficult Transition

 Upon transplantation, apparently beginning on the day of transplant, these findings convey a shift in adolescent patient experience. This phase, emerging on the temporal line of during and immediately after the transplant surgery and related hospitalization, transpired as an experience that was deemed to be a difficult transition. Within this experience, a range of emotions were consistently described including fear, anxiety, joy and hope. The adjustment and shifts within this developmental and adaptive phase appeared to be immensely challenging for youth and emerged as being of a different
nature than that of pre-transplant experience. Participants’ experiences appeared to comprise some unique adaptive tasks. Specifically, participants shared vivid memories related to strenuous and often undesirable physical rehabilitation, painful treatment procedures and adverse side-effects of the medication regimen. These findings are supported by those of Green et al. (2007) which revealed painful and frightening aspects of hospitalization and care including children’s post-transplant experiences punctuated by medically-related and painful procedures such as needle sticks and biopsies, as well as perceived negative impacts associated with medication (e.g., cyclosporine) such as altered and undesired appearance.

The phase immediately following hospitalization embodied a commonly described challenge of adjusting to changes associated with a new heart and the treatment sequelae related to that change. Moreover, participant experiences that were presented in this phase of adjustment included integration in new or revised elements of daily life. For instance, these findings illustrate the sometimes arduous return to the education system, which for some adolescents appeared to be shrouded with stress including concerns spanning cognitive, social and integrative elements. Examples of such daily adjustment challenges include seeking to reintegrate and achieve desirable academic functioning which often proved difficult. For some children, social adjustment engendered issues of reintegrating peer relationships which in several instances, sadly represented bullying and teasing as a specific result of the transplantation process or changed physical symptoms or appearance. These various school-related results concur with previous findings from Wray et al. (1992, 2005) in which transplant recipients obtained lower scores on all
academic parameters compared with the normative group, and with findings from Green et al. (2007) that identified issues around school attendance, teasing and bullying.

In this post-transplant time, these findings point to processes of struggle and adjustment, whereby recipients grapple with the presence of a foreign, life-giving organ within their body. For instance after transplant several adolescents in this study appeared to struggle psychologically with accepting a foreign organ – their new heart – as their own and the meaning they attributed to this donated organ. This appears to be manifested or related to a range of responses that emerged in these findings such as feelings of sadness or guilt regarding the death of the donor and/or thoughts or questions about potentially acquiring qualities or characteristics of the donor via the receipt of their heart. Almost all of the participants in this sample voiced appreciation to the donor, with many speculating extensively about the donor and longing for donor information. An emergent complex relationship with the imagined donor transpired. This process of perceived assimilation to the identities and components represented by the new organ appears centrally linked to broader concerns about the donor’s heart and the effect of somebody else’s heart on the possible development of an alternative personality. These findings are consistent with and build upon previous findings reported in the literature (Bunzel et al., 1992a, 1992b; Inspector, Kutz & David, 2004; Kaba et al., 2005; Kuhn, Davis & Lippmann (1988); Rauch & Kneen, 1989; Rogers, 1989; Sanner, 2001), and highlight the complex process of integrating and adapting to heart transplantation. These findings invite future exploration addressing what may involve elements of a newly formed identify that emerges with a heart transplant.
An Awakening and Transformation

With post-transplant stability over time, a notable shift in experience commonly unfolded. At this point, participants appeared to recognize within themselves marked improvement in health and increased energy. This appeared to engender a bodily and inter-psychic shift of recognizing physical change and appreciating a new (or renewed) experience and understanding of being able to engage more in daily activities. This recognition and change in bodily and psychoemotional comportment and experience emerged, in these data, along with a pervasive and apparently lasting sense of gratitude for the new heart – which was now deemed to be a source of what was commonly seen to be a new active and satisfying life. As such, almost all of the participants enjoyed few physical limitations post-transplant, and were able to participate in age-appropriate activities, including attending school regularly. However, these positive outcomes appeared reminiscent of a shifting or transformed understanding of who they were as persons with a well-functioning heart. These findings hold implications and meanings about adolescents’ emerging identities and what their daily life and future looked like. They appeared to widen their view of emergent possibilities for engaging in and actively pursuing desired elements in their social world. In short, this phase appeared as an awakening whereby transplanted youth viewed themselves as more active, healthy human beings, a state of well-being and quality of life seldom imagined or achieved prior to transplantation.

These findings corroborate, amplify and deepen those of other researchers. For instance, an improved physical status and the ability to return to age-appropriate activities were
reported in studies by Lawrence & Fricker (1987), Pennington et al. (1985), Serrano-Ikkos et al. (1999), Sigfusson et al. (1997), Spurkland et al. (2001) and Uzark et al. (1992). Improvement in physical functioning was substantially related to psychosocial well-being and perceived quality of life. This relationship between physical functioning and psychosocial well-being and quality of life is evident in the findings of Wray et al. (1992). The increased ability to join their peer group in various enjoyable social and recreational activities, such as playing in the playground, recess, physical education and ‘hanging out’ was a major focus for all study participants. Findings by Green et al. (2007) included a key theme of ‘Doing What Kids Do’, and encompassed data related to opportunities and ability to participate in desired recreational and social activities. Participants interpreted and ‘fit’ the experience of transplantation into their lives by normalizing it and sharing stories about incorporating medical regimens into their daily routine. These findings support previous work by Green et al. (2007), which found that pediatric heart transplant recipients did not want their transplant status to dominate their lives and worked to avoid keeping illness in the foreground.

Like these important findings that other researchers have reported, participants in this program of research clearly came to a personal understanding and experience of expressed satisfaction with their present life and a strong sense of optimism about the future. While this level of satisfaction and optimism indeed varied among individual adolescents, these data largely identify a preponderance of emerging comfort and peacefulness in the wake of post-transplantation experience in terms of who these young people see themselves to be vis-à-vis healthy, integrated, generally happy human beings.
These findings are encouraging as we think about the investment and adjustments imposed on children and adolescents undergoing transplantation. In thinking about their view of the future and risk for possible graft rejection, adolescents consistently did not worry about or fear rejection, re-transplantation or death, and they generally expressed a determination to ‘focus on the present’. This consistently positive outlook appears epitomized in words of a participant who spoke of his resolve to “live life to the fullest”. Moreover, these findings demonstrate the potential and common experience for adolescents to come eventually to a new place in which the self is viewed to be stronger and better after, and as a result of, their transplant experience. Despite the many challenges after transplantation, this new-found realization appeared to envelope elements of recognizing transplantation and life itself as a ‘wonderful gift’, and a hope for it not to be taken for granted or downplayed. Clearly, these findings suggest a profundity of insight and experience among transplanted youth.

In summary, these findings illuminate the quality of life of adolescents who have undergone heart transplantation to be rich and developmentally or incrementally nuanced. There appears to be a progressive trend from poor to better perceptions of well-being. These findings invite further exploration at each of these stages as there is much yet unknown about the subtle and profound shifting in post-transplant experience including what may precipitate, facilitate, limit and moderate this progression. Notwithstanding the many questions that have emerged from these findings, this program of research has unveiled the potential for a notable protracted post-transplant state of enhanced life satisfaction. Clearly survival is not the sole aim or benefit of a transplant; rather, goals of
a renewed self emerge from this surgical procedure as well as its arduous process of demanding physical rehabilitation and its vigilant requirement of imposed self-care. Despite these rigors, these findings uniquely point to what has appeared in this analysis to be an emerging ‘transplanted self’, that being a transformative process.

6.2  A Transformative Process

Results from this program of research, as described above, illuminate pediatric transplantation in its potentially transformative nature, whereby the trauma of transplant may ultimately result in positive outcomes that go beyond merely feeling better and/or effectively coping and adjusting well. These findings thus add depth in building on previous work that generally focuses on and describes the inherent challenges that accompany transplantation. Of substantial contribution to the literature, these data offer the emergent expansive role of positive experience yielded from the transplantation.

Although many of the pediatric transplant recipients reported distress and struggle in the aftermath of transplantation, nearly all cited ultimate benefits or positive changes. This conceptual framework suggests that transplantation can provide the impetus for meaningful transformation and growth, in such a manner that one’s functioning and well-being are deeply enhanced. There appears to be a subtle difference in that the literature to date has largely depicted pediatric transplantation from a defensive posture, that is that transplant is a necessary guard against the risk of death and morbidity. Yet, these data – reflecting the words and perceptions of adolescents embodying the experience of transplantation – posture transplantation differently by suggesting that the transplant, for these youth, generally has offered hope, personal change, reflectiveness and gratitude.
Recasting transplantation not just as a defense against devastating illness, but potentially as a generative, hopeful condition and opportunity offers novel theoretical and clinical fodder for further inquiry.

In considering this emergent sense of who one becomes with a transplant, these findings appear to unveil three dimensions of positive transformations experienced by participants. Emergent levels of transformational shift appear to engender self-perception, including a greater sense of personal strength and recognition of coping abilities. Findings appear to illustrate the potential for transplanted adolescents to come to a new understanding that they can survive and independently, or perhaps with support, cope with current and future challenge. This belief and apparent emergent trust in the self to achieve personal strength speaks to an increasingly internalized sense of mastery and self-efficacy possibly as part of feeling better and more in control of one’s health. Regardless of how this appeared to emerge participants within this sample generally found a semblance of new-found confidence and satisfaction. Second, following transplantation participants demonstrated greater meaningfulness in interpersonal relationships. The experience of having undergone transplant brought many participants closer to loved ones (e.g. parents, siblings, grandparents, friends). They expressed a greater appreciation for relationships with family and friends and for the opportunity to spend time together. Third, almost all of the participants in this sample discussed ways in which their transplant had altered their life philosophy or general view of life and their place therein. Generally, this entailed a re-ordering of priorities, a greater appreciation for life, a renewed sense of purpose and/or a richer spiritual life. In these instances,
transplant appears to have offered an opportunity for an orientation to life that comprised
an enjoyment of life and an investment of energy in the present rather than worry about
the future or sadness about the past. New possibilities appeared to emerge which may
include a new and different path or set of guiding assumptions. Having undergone
transplant thus seems to offer the potential to set in motion the unfolding of a sense that
one had been spared, and that this gift of a second chance should be appreciated and in
some cases, celebrated. The notion of a ‘second chance’ seems to generally be related, at
least in these findings, to a profound sense of hope and optimism. Participants described a
greater appreciation for the preciousness of life as participants described emerging and
unfolding meaning for their daily life and their existence as a human being. These
findings thus seem to reveal existential shifts of whom one is in the world. Accordingly,
these findings emerge in reflecting pediatric heart transplant recipients not as merely
coping, but rather as developing persons demonstrating incremental growth and positive
changes in life outlook, identity, sense of self and meaning.

The proposed framework seems to resonate well with the theoretical-philosophical
approach to quality of life that focuses on the individual’s possibilities in three
fundamental areas of life: being, belonging and becoming (Renwick & Brown, 1996).
The transformative nature of transplantation appears to have had a positive impact on
many of the subcomponents subsumed within being (e.g. physical being encompassing
physical health, mobility and nutrition; psychological being embodying individuals’
feelings, cognitions and evaluations of themselves; spiritual being consisting of personal
values and spiritual beliefs), belonging (e.g. physical belonging including the feeling of
being at home in their physical environment, and *social belonging* focusing on meaningful relationships with others) and *becoming* (e.g. *leisure becoming* referring to participation in social and recreational activities, and *growth becoming* encompassing the promotion of new skills and knowledge and adapting to changes in life) (Renwick & Brown, 1996). The process of transplantation may have permanently altered the importance or meaning pediatric recipients attach to each of these dimensions, as well as the extent of their level of enjoyment, thus resulting in a higher quality of life. This perception of an enhanced quality of life is influenced by the fact that following heart transplant pediatric recipients appear to possess a stronger sense of control with respect to important possibilities in their lives, as well as a greater sense of potential opportunities for growth and change.

The results from this program of research appear to illuminate a relatively new phenomenon in this field. As these findings have unfolded, consistencies with literature in the area of post-traumatic growth have been noted. As these notions of transformation were not the focus of this research and have been ‘unearthed’ in this exploratory process, these ideas are presented as tentative observations of the data, meriting further scrutiny in future research. This exciting area for future investigation is discussed further in the research implications section.

Notwithstanding this caution and recognition that the focus of this analysis and dissertation is not on the literature on *post-traumatic growth*, this emerging area in heart transplantation appears consistent with notions of ‘positive psychological change"
experienced as a result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004, p.1). A cursory application of this approach suggests that traumatic events and circumstances can destabilize or shatter assumptions about one’s self and the expected course of one’s life, setting in motion attempts to cope and adapt. Some individuals are able to rebuild their assumptive world in order to accommodate the trauma, specifically the experiences of vulnerability, helplessness and perceived randomness, and find that they have arrived at new understandings and revisions of the self and the world (Janoff-Bulman, 2004). Yet this cursory review of this body of literature appears to reveal that as shifted assumptions are rebuilt over time, individuals may begin to recognize positive changes and a transformation in their functioning and well-being that exceeds pre-trauma levels (Tedeschi & Calhoun, 1996).

The phenomenon of post-traumatic growth has been reported after exposure to various traumatic events, including natural disasters (Tang, 2006; Thompson, 1985), accidents (Bulman & Wortman, 1977), war (Helgeson, Reynolds & Tomich, 2006) and other forms of adversity, such as bereavement (Calhoun & Tedeschi, 1989-1990; Engelkemeyer & Marwit, 2008) and life-threatening illness (Affleck, Tennen, Croog & Levine, 1987; Cordova, Cunningham, Carlson & Andrykowski, 2001; Milam, 2004). Although post-traumatic growth has generated considerable interest in the adult literature, few studies have examined the post-traumatic growth construct among children and adolescents. Early evidence suggests the possibility that traumatized children and adolescents can display post-traumatic growth (Cryder, Kilmer, Tedeschi & Calhoun, 2006; Milam, Ritt-Olson & Unger, 2004).

While the literature on pediatric transplantation tends to stress the negative physical and psychosocial sequelae of transplantation, the findings from this program of research invite consideration of transplantation in light of the potential to be not only a traumatic event requiring recovery, but also a potential catalyst for growth and personal transformation. Although the transplant experience certainly can be a source of distress, it also may serve to foster personal growth and positive change. While the intense suffering of illness and transplantation cannot be minimized or glossed over, the experience appears, from these findings, to have a dimension that may offer a particular element of transformation engendered in a perceived new lease on life, meaning and personal growth. These findings raise the possibility that pediatric heart transplant recipients might not only survive transplantation, but may thrive and achieve a newfound quality of life perhaps not attainable prior to transplantation.
6.3 Study Limitations

This study has several limitations. First, those adolescent heart transplant recipients who were not willing to participate may have different experiences and perceptions, and because of their non-inclusion these were obviously not represented in the findings. Second, this research focused exclusively on the perceptions of adolescent heart transplant recipients, without relating these to the perceptions of other individuals including parents, siblings, teachers or other caregivers. However, given the complexity of the inherent issues and the lack of knowledge to date about pediatric transplant recipients’ lived experience, the study’s focus on recipients is justified. Moreover, there is increased recognition that children’s and adolescents’ viewpoints should be at the centre of research pertaining to their health and well-being (Eiser & Morse, 2001a; Quinn et al., 2002; Rosenbaum & Saigal, 1996; Social Development Canada, 2004). Third, the investigator had clinical experience with the study population which may have influenced aspects of the research process, including creation of the interview guide, data collection and/or analysis. To minimize potential issues emerging from this familiarity, trustworthiness was established. The use of triangulation, member-checking and referential adequacy served as means of verifying the relevance and accuracy of emergent themes. Conversely, the investigator’s familiarity and experience with the study population may have offered numerous benefits, possibly including engagement with study participants and a deepened appreciation for their lived experiences.
6.4 Implications for Clinical Practice and Future Research

The theoretical framework that emerged from this program of research offers direction to improve the care provided to adolescent heart transplant candidates and recipients who face numerous physical, psychological and social challenges. A multi-disciplinary approach is necessary to meet the many and varied needs of this patient population, and appropriate services are needed to help them manage the multiple demands of transplantation along with the normal developmental tasks of adolescence. Health-care practitioners can play an important role in enhancing resources and coping, and in promoting psychosocial adaptation and improved quality of life for these adolescents.

It is critical that a family-centered approach to care be implemented. Family-centered care is a philosophy of care that is grounded in mutually beneficial partnerships among health-care providers, patients and families. Some of the core concepts that underlie family-centered care include dignity and respect, information sharing, participation and collaboration. As health-care practitioners it is important to listen to the voices of the children and adolescents and to incorporate their knowledge, values and beliefs into the plan of care.

Striving to promote the health and well-being of pediatric heart transplant patients and their families can involve direct and indirect clinical interventions, education and research. There is a need not only for early comprehensive psychosocial assessment prior to transplantation, but also for systematic support and intervention throughout the transplant process. Health-care practitioners who are aware of the multitude of issues
that may arise throughout the transplant trajectory can prepare patients and their families for the experiences they may encounter and help them to expand their resources. Preventive interventions can teach patients to recognize and reduce sources of stress and help them strengthen their personal competence, coping skills and social resources (Kaba et al., 2005). A multifaceted approach is needed to equip adolescent transplant recipients with the skills and capacities they need to assimilate a new organ, achieve a sense of normalcy and gain acceptance among their peers. Sustained psychosocial and emotional support can help patients manage negative emotions and experiences, as well as assist with issues pertaining to self-esteem, body image and peer relationships. Psychosocial supports may include both formal support systems, such as counseling services, and informal support systems, such as patient support groups. Innovative Internet- or technology-based interventions that offer information and social, decision-making and behavioural support could be considered for the adolescent transplant population (Tong, Morton, Howard & Craig, 2009).

As school plays a major role in the lives of children and adolescents, more attention and investment are needed to provide school-based support. Early intervention and close liaisons with schools are needed to reduce psychological morbidity, enhance adaptation within the school environment and enhance overall achievement (Wiel, Rodgers & Rubovits, 2006). These supports may include: a) social skills training programs to provide adolescents with the necessary strategies to answer questions from peers and teachers about their transplant, b) educational programs for parents and school personnel delivered by the health-care team and c) greater interaction with schools pre and post-
transplant to plan and provide academic, emotional, school re-entry and behavior support (Tong et al., 2009; Weil et al., 2006). These necessary instrumental and emotional supports would address children’s, parents’ and teachers’ needs, including academic placement, psychological adjustment of the child or adolescent, peer concerns, staff anxiety and education about transplant, medications, side-effects and risks (Weil et al., 2006).

While it is necessary to understand the distressing negative implications that can surround transplantation, acknowledging the possibility of growth and the potential for transformation and positive change is also important for practitioners and researchers. There is a need to frame clinical and research inquiries to locate transplantation within a continuum of transformational growth that includes, but is not limited to, stress, coping and generative growth and change. Empirical investigations examining the phenomenon of post-traumatic growth within the pediatric transplant population are necessary and could yield valuable information for practitioners, serving to guide and inform aspects of their assessments and interventions (Calhoun & Tedeschi, 2006). Documenting whether post-traumatic growth is possible, and identifying factors or conditions associated with post-traumatic growth, would assist practitioners in (a) recognizing and assessing positive factors and (b) pursuing means to facilitate the development or enhancement of such factors and foster post-traumatic growth (Tedeschi & Kilmer, 2005). While practitioners cannot create growth for clients/patients, they can facilitate the process to achieve growth through interventions that promote coping strategies, benefit finding and meaning-making processes. This framework of transformational change and growth is consistent
with many of the competence-enhancement, strength-based and skill-building approaches increasingly utilized in clinical practice. It fits well with the recent changes to focus upon what ‘goes right’ in development, emphasize positive outcomes, and study strength, virtue and growth (Cowen, 1994; Seligman & Csikszentmihalyi, 2000).

Given the relative lack of research about quality of life and psychosocial implications following pediatric heart transplantation, there is a continuing need to add to the growing body of research that examines the experiences of pediatric heart transplant recipients and their families and explores the nuances of potential post-traumatic growth. Longitudinal studies are also needed that examine the complexities of life post-transplant, as they are experienced and given meaning by pediatric recipients over time. Little is known about the long-term realities of pediatric heart transplant recipients’ lives or the impact of transplantation over their life course. An important next step would be to test these research findings using a multi-site sample. This study should also be replicated with a younger cohort of heart transplant recipients in order to determine whether the findings are representative of the perceptions of younger patients representing a broader developmental spectrum. Further research is also warranted that explores the lived experiences and quality of life of other family members such as parents, siblings and extended caregivers. Examining their experiences and perceptions would illuminate further how families are impacted by pediatric heart transplantation.
6.5 Conclusion

The primary strength of this research is the in-depth examination of adolescents’ experience of undergoing heart transplantation. Drawing on adolescents’ own perspectives as a basis for understanding their transplant experiences addresses a significant gap in the literature. It also balances the methodological limitations of previous research that relied primarily on quantitative approaches and/or on proxy reports of adolescent transplant recipients’ quality of life and psychosocial functioning. The findings from this research provide a richer understanding of adolescent heart transplant recipients’ experiences than has previously been available and offer new insights about quality of life following pediatric heart transplantation.

In summary, findings indicate that adolescent heart transplant recipients are profoundly affected by the process of transplantation. This research identifies that heart transplantation, which may contain elements of suffering and loss, may ultimately enhance the recipients’ overall quality of life. Results suggest the possibility that adolescent heart transplant recipients not only adapt in the aftermath of transplant, but seemingly transform it into a meaningful and growth-enhancing experience. The experiences of pediatric transplant recipients indicate that the frightening and confusing aftermath of heart transplant can be fertile ground for unexpected outcomes, with many of them undergoing fundamental changes in their lives that they view as highly positive. Heart transplantation can afford recipients the opportunity to discover new strengths within themselves, revitalize their relationships and enhance the meaning of their lives. Adolescent heart transplant recipients appear to be living life in ways that, at least from
their point of view, are richer and perhaps more meaningful. This ability to embrace life may be one of the potential gifts transplant recipients create out of their transplant experience.

In conclusion, this program of research has identified heart transplantation to be a complex multi-layered process of difficulty, adjustment and growth. This process invites thoughtfulness in considering clinical and research steps forward. Fostering growth and quality of life among children and adolescents are important priorities in the field of heart transplantation. Finally, ensuring well-funded resources for these youths and their families, and continuing to examine empirically and respond effectively to their experiences, constitute ongoing aims worthy of pursuit.
References


children who have survived longer than five years. *Journal of Pediatrics* 130(6): 862-871


Webster’s new universal unabridged dictionary (1983). Dorset & Baber: Cleveland, OH


Title of Research Project:
Quality of Life Following Pediatric Heart Transplantation

Investigator(s):
Samantha J. Anthony (PI) Department of Social Work (416) 813-7006
Beverley J. Antle Department of Social Work (416) 813-6788
Anne I. Dipchand Division of Cardiology (416) 813-6674
Brian W. McCrindle Division of Cardiology (416) 813-7610
Cheryl Regehr Faculty of Social Work (416) 978-6314
Lori J. West Faculty of Medicine (780) 492-3200

Purpose of the Research:
Heart transplantation has saved many children with serious heart abnormalities. While survival and functional measures are usually emphasized to evaluate transplantation, quality of life is an important outcome of transplantation. We would like to get a better understanding of how your child’s quality of life is after receiving his/her new heart. This study will help us learn about your child’s overall physical functioning and psychosocial well-being.

Description of the Research:
Your child will be asked to participate in a face-to-face interview, where they will be asked questions about what life is like for them after having a heart transplant. The interview will be approximately 1 hour. A review of your child’s health record will be conducted to obtain important medical variables (such as time of transplant, diagnosis, etc.)

New information from this study or other studies may affect whether your child wants to continue to take part in the study. If this happens, we will tell you about this new information.

Potential Harms:
We know of no harm that taking part in this study could cause your child.

Potential Discomforts or Inconvenience:
Discomforts or inconveniences associated with participation in this study include the time commitment required to be interviewed.
Potential Benefits:
This study will help to better serve individual heart transplant recipients, as well as the heart transplant population as a whole, by providing information that is currently not available to transplant professionals. This information will be used to improve the quality of the care provided to the heart transplant population as a whole.

Participants will receive a brief summary of the research findings.

Confidentiality:
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this.

For example, the law could make us give information about you
- If a child has been abused
- If you have an illness that could spread to others
- If you or someone else talks about suicide (killing themselves), or
- If the court orders us to give them the study papers

SickKids Clinical Research Office Monitor, employees of the company funding the study, or the regulator of the study may see your health record to check on the study. For example, people from Health Canada Health Products and Food Branch, U.S. National Institutes of Health, and U.S. Food and Drug Administration, if necessary, may look at your child’s records.

By signing this consent form, you agree to let these people look at your child’s records. We will put a copy of this research consent form in your child’s patient health records.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. Following completion of the research study the data will be kept as long as required by the SickKids “Records Retention and Destruction” policy. The data will then be destroyed according to this same policy.

Reimbursement:
We will pay for all your expenses for being in this study eg., meals, babysitters, parking and getting you to and from SickKids. If you stop taking part in the study, we will pay you for your expenses for taking part in the study so far.

Participation:
Participation in this research is voluntary.

If you choose to let your child take part in this study you can take your child out of the study at any time. The care your child gets at SickKids will not be affected in any way by whether your child takes part in this study.
New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

During this study we may create new tests, new medicines, or other things that may be worth some money. Although we may make money from these findings, we cannot give you or your child any of this money now or in the future because you or your child took part in this study.

We will give you a copy of this consent form for your records.
Parent/legal guardians of subjects should be aware that assent may be required from their child.

If your child becomes ill or is harmed because they took part in this study, we will treat them for free. Your signing this consent form does not interfere with your legal rights in any way. The staff of the study, any people who gave money for the study, or the hospital are still responsible, legally and professionally, for what they do.

**Sponsorship:**
There is no sponsor/funder of this research.

**Conflict of Interest:**
None of the investigators involved in this study appear to have a conflict of interest.

**Consent:**
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of having my child take part in this study. I understand that I have the right to refuse to let my child take part in the study. I also have the right to take my child out of the study at any time. My decision about my child taking part in the study will not affect my child’s health care at SickKids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private. You will give no one information about my child, unless the law requires you to.
6) I understand that no information about my child will be given to anyone or be published without first asking my permission.
7) I have read and understood pages 1 to _____ of this consent form. I agree, or consent, that my child________________ may take part in this study.
If you have any questions about this study, please call Samantha Anthony at (416) 813-7006.

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at (416) 813-5718.
Title of Research Project:
Quality of Life Following Pediatric Heart Transplantation

Investigator(s):
Samantha J. Anthony (PI) Department of Social Work (416) 813-7006
Beverley J. Antle Department of Social Work (416) 813-6788
Anne I. Dipchand Division of Cardiology (416) 813-6674
Brian W. McCrindle Division of Cardiology (416) 813-7610
Cheryl Regehr Faculty of Social Work (416) 978-6314
Lori J. West Faculty of Medicine (780) 492-3200

Purpose of the Research:
Heart transplantation has saved many children with serious heart abnormalities. While survival and functional measures are usually emphasized to evaluate transplantation, quality of life is an important outcome of transplantation. We would like to get a better understanding of how your quality of life is after receiving your new heart. This study will help us learn about your overall physical functioning and psychosocial well-being.

Description of the Research:
You will be asked to participate in a face-to-face interview, where you will be asked questions about what life is like for you after having a heart transplant. The interview will be approximately 1 hour.
A review of your health record will be conducted to obtain important medical variables (such as time of transplant, diagnosis, etc.)

New information from this study or other studies may affect whether you want to continue to take part in the study. If this happens, we will tell you about this new information.

Potential Harms:
We know of no harm that taking part in this study could cause you.

Potential Discomforts or Inconvenience:
Discomforts or inconveniences associated with participation in this study include the time commitment required to complete the questionnaire and be interviewed.

Potential Benefits:
This study will help to better serve individual heart transplant recipients, as well as the heart transplant population as a whole, by providing information that is currently
not available to transplant professionals. This information will be used to improve the quality of the care provided to the heart transplant population as a whole.

Participants will receive a brief summary of the research findings.

**Confidentiality:**
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this.

For example, the law could make us give information about you
- If a child has been abused
- If you have an illness that could spread to others
- If you or someone else talks about suicide (killing themselves), or
- If the court orders us to give them the study papers

SickKids Clinical Research Office Monitor, employees of the company funding the study, or the regulator of the study may see your health record to check on the study. For example, people from Health Canada Health Products and Food Branch, U.S. National Institutes of Health, and U.S. Food and Drug Administration, if necessary, may look at your records.

By signing this consent form, you agree to let these people look at your records. We will put a copy of this research consent form in your patient health records.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. Following completion of the research study the data will be kept as long as required by the SickKids “Records Retention and Destruction” policy. The data will then be destroyed according to this same policy.

**Reimbursement:**
We will pay for all your expenses for being in this study eg., meals, babysitters, parking and getting you to and from SickKids. If you stop taking part in the study, we will pay you for your expenses for taking part in the study so far.

**Participation:**
Participation in this research is voluntary.

It is your choice to take part in this study. You can stop at any time. The care you get at SickKids will not be affected in any way by whether you take part in this study.

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.
During this study we may create new tests, new medicines, or other things that may be worth some money. Although we may make money from these findings, we cannot give you any of this money now or in the future because you took part in this study.

We will give you a copy of this consent form for your records. If you become ill or are harmed because you took part in this study, we will treat you for free. Your signing this consent form does not interfere with your legal rights in any way. The staff of the study, any people who gave money for the study, or the hospital are still responsible, legally and professionally, for what they do.

**Sponsorship:**
There is no sponsor/funder of this research.

**Conflict of Interest:**
None of the investigators involved in this study appear to have a conflict of interest.

**Consent:**
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at SickKids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private. You will give no one information about me, unless the law requires you to.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I have read and understood pages 1 to _____ of this consent form. I agree, or consent, to take part in this study.

____________________  ____________________________
Printed Name of Subject & Age  Subject's signature & date

____________________  ____________________________
Printed Name of person who explained consent  Signature & date

____________________  ____________________________
Printed Witness’ name (if the subject/legal guardian does not read English)  Witness’ signature & date

If you have any questions about this study, please call Samantha Anthony at (416) 813-7006
If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at (416) 813-5718
Title of Study
Quality of Life Following Pediatric Heart Transplantation

Investigator(s)
Samantha J. Anthony (PI)  Department of Social Work  (416) 813-7006
Beverley J. Antle  Department of Social Work  (416) 813-6788
Anne I. Dipchand  Division of Cardiology  (416) 813-6674
Brian W. McCrindle  Division of Cardiology  (416) 813-7610
Cheryl Regehr  Faculty of Social Work  (416) 978-6314
Lori J. West  Faculty of Medicine  (780) 492-3200

Why are we doing this study?
Children who have very sick hearts that cannot beat for them, sometimes get a new heart. We would like to get a better understanding of how your quality of life is after receiving the new heart. This study will help us learn about your health and well-being, how you are doing overall, about school, about your friends and family, about everyday activities that you do, and how you feel in general. This information will help us understand what life is like after heart transplantation for our patients.

What will happen during the study?
You will be asked to do a face-to-face interview. The interview will be about 1 hour long. Interviews will be tape-recorded and you will need to sign a separate consent form.

Are there good things and bad things about the study?
This study may help us to make the care and services that we give to patients and families at SickKids better. There are no known harms from being in this study.

Who will know about what I did in the study?
No one will know that you were in the study.
If we feel your health may be in danger, we may have to report your results to your doctor.

Can I decide if I want to be in the study?
Nobody will be angry or upset if you do not want to be in the study. You can decide if you want to be in this study. During the study, if you want to stop, please let us know. If you decide not to participate in the study, it will not change the care you receive at SickKids in any way. We are talking to your parent/legal guardians about the study and you should talk to them about it too.

**Assent:**

"I was present when ______________________________ read this form and said that he or she agreed, or assented, to take part in this study”.

__________________________  ______________________
Printed Name of person who obtained assent  Signature & Date
Appendix B
Interview Guide

The project will be introduced by the research interviewer first.

1. Tell me a little bit about yourself and your family
   Probes: How old are you? Where do you live? Who’s in your family?

2. Do you go to school?
   Probes: What school do you attend and what grade are you in? Tell me a little bit about what it is like at your school? What’s your favourite thing? Anything you don’t like?

3. What do you like to do for fun?
   Probes: Daily activities? Things you do in your spare time? Who do you play with/hang out with? What sorts of things do you do together? Who would you say is your closest friend?

4. Do you remember what life was like before you had a heart transplant?
   a. If yes, can you tell me a little bit about what it was like?
   b. If no, can you tell me what you know from others about what it was like for you?

5. What has it been like since you’ve had a heart transplant?
   Probes: Are there things that you can do now that you couldn’t do before? How do you handle the medical visits and tests? Some kids say to us that they feel different, others don’t say they feel much different, what has it been like for you?

6. What has it been like with your family, friends and school since you’ve had the transplant?
   Probes: Do you talk much about the transplant? How do you explain what it is like having a heart transplant to others? Some kids feel like they are treated different now? Is this true for you? Can you give me some examples?

7. If you are having a bad day, what makes you feel better? Do you have bad days very often? Can you tell me a little bit about those days?

8. If you met someone your age who needed a heart transplant what would you say to them?

9. Is there anything you would like parents of heart transplant recipients to know, that would make like easier for you as kids? What about your health care team, anything advice for us to make things better for kids having a heart transplant?

10. You’ve sure been helpful to us and we’ve talked about a lot of things. Anything else you would like to add?
Dear

We are writing to let you know about a study we are conducting called, “Quality of Life Following Pediatric Heart Transplantation”. In conducting this study, we are hoping to better understand the quality of life and day-to-day experiences of heart transplant recipients. This study will help us to better meet the needs of individual heart transplant recipients and their families, as well as the heart transplant population as a whole, by providing information that is currently not available to transplant professionals. Participation in the study will involve a face-to-face interview, during which questions will be asked about your life as a heart transplant recipient. We expect that the interview will last approximately 1 hour.

Feel free to call us for more information or if you are interested in participating in this study. Someone will call you in about two weeks to answer any questions you may have about the study and to inquire about your possible interest in participating. Please note that participation in the study is entirely optional. If you would prefer not to participate, that is fine. If you decide not to participate, the care that you receive at The Hospital for Sick Children will not be affected.

Thank you for taking the time to read this letter and considering participating in the study. Please feel free to contact me directly at 416-813-7006 if you have any specific concerns or questions.

Sincerely,

The Research Team
Samantha Anthony
(416) 813-7006
Dr. Beverley Antle
Dr. Anne Dipchand
Dr. Brian McCrindle
Dr. Cheryl Regehr
Dr. Lori West