The new normal:

**A Bourdieusian examination of living into young adulthood being a
paediatric heart transplant recipient**

by

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Lawrence S. Bloomberg Faculty of Nursing
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Abstract

Improved success of paediatric cardiac transplantation has resulted in increased survival of recipients into young adulthood (19 to 29 years of age). Young adults who received a heart transplant during childhood have experienced multiple life sustaining procedures. As survival and longevity increase, it is clear that transplant recipients experience negative physiological, psychological and social sequelae. With heart transplant offering individuals a chance to extend life into young adulthood, recipients need lifelong care and at age 18 they will transition from paediatric to adult healthcare facilities. The study addressed young adults circumstances of existence and their competing interests within various social environments. This research project applied Pierre Bourdieu's theoretical concepts of habitus, field and capital, to conceptualize and engage with empirical knowledge production about young adults who have received a heart transplant during childhood. Using visual methodology, focused open-ended interviews were conducted with 12 young adults who had a heart transplant during childhood. Bourdieu's work

provided a theoretical framework to investigate transplant recipients' identities and social re-positioning in relation to dominant discourses of organ transplant and shifting relationships with health services providers. This study involved an iterative process to identify recipients' encounters and new compositions in relation with others, in order to answer the research objective. These findings highlight that young adult transplant recipients struggle with relational dispositions that excludes them from various fields of social engagement; their struggle and exclusion from various fields is symbolic and is embedded in the structure of the dominant social order of the field from where they become excluded; the social order is taken up and embodied, leading young transplant recipients to practices of accommodation and "normalization". Changes in healthcare practices, attuned to person implications and peer relationships can begin to address young transplant recipients' contradictory social positions. Such an approach can potentially lead to improvement in ongoing care and services for young adults who require a lifetime of care. At the same time, it will allow nurses to better prepare and counsel young individuals who are preparing for a heart transplant.

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CHAPTER 1: INTRODUCTION

Introduction

Improved success of paediatric cardiac transplantation has resulted in increased survival of recipients into young adulthood (19 to 29 years of age). Young adults who received a heart transplant during childhood are a group of individuals who have experienced multiple life sustaining procedures. As survival and longevity increase, it has become clear that transplant recipients experience negative physiological, psychological and social sequelae. With heart transplant offering individuals a chance to extend life into young adulthood, recipients need lifelong care and at age 18 transition from a paediatric to an adult healthcare facility.

There was a critical need to better understand young adults' perception of heart transplant and the potential contrast between the experiences of young adult recipients and 'typical' heart transplant recipients, who received their transplant at a significant later stage in their life and are predominantly male (Taylor et al., 2006). A limited understanding of what it is like to be a young adult living with a heart transplant ultimately raised questions about the appropriateness of current clinical practice in Canada.

I approached the project as a white male nurse and graduate student, who immigrated to Canada fourteen years ago from Austria. Over the last twelve years, I have gained extensive transplant and cardiology experience working as an advanced practice nurse in a tertiary healthcare facility. More recently, I was recruited into the position of a research associate, which enabled me to collaborate with a multidisciplinary team on two very innovative qualitative research projects involving adult transplant participants and children with disabilities. My past

and present, shaped by my own positionality, orients my way of constructing objects within this study by stressing issues of importance and providing a means of thinking relationally about those issues. Thus, throughout this research study, I utilized Bourdieu's characteristics of reflexivity. This meant I employed the same epistemological approach of knowledge production to myself, in order to reflect on my own disposition and by doing so provided transparency about the production of knowledge of young adult transplant recipients. Thus, reflecting on my own positionality was not only fundamental during the analysis process, but needed to be present from the beginning of the study.

Introduction to paediatric heart transplant

Cardiomyopathy is the primary cause for heart transplant in individuals > 1 year of age (Dipchand et al., 2009) and is a progressive clinical and pathophysiological syndrome that can be caused by cardiovascular and non-cardiovascular abnormalities (Hsu & Pearson, 2009). The disease results in characteristic signs and symptoms including: edema, respiratory distress, growth failure, and exercise intolerance. Frequently the disease progresses to circulatory, neurohormonal, and molecular derangements (Hsu & Pearson, 2009). Overall, 40% of children who have been diagnosed with cardiomyopathy and show symptoms of heart failure will either receive a heart transplant or die within 5 years of diagnosis (Dipchand et al., 2009). While there are spectrums of medical options available to manage children with cardiomyopathy, heart transplantation is indicated as therapy in advanced heart failure (Canter et al., 2007).

Concomitantly, over the last 10 years enhanced staged palliative surgical procedures have resulted in improved survival of individuals with congenital heart disease (Bounce, Aurora, Edwards, & Taylor, 2007). Initially, heart transplantation was the primary therapy for left heart

anomalies like hypoplastic left heart syndrome, but due to the shortage of available organs individuals frequently died while waiting for a transplant (Bounce et al., 2007). The success of reparative or palliative surgery in individuals with congenital heart disease has led to a decreased use of heart transplant as primary therapy and commonly individuals survive into adulthood (Bounce et al., 2007). Since these procedures are rarely curative, however, ongoing morbidity and mortality persists and heart transplantation might still be performed after previous palliative congenital heart disease surgery (Bounce et al., 2007).

Paediatric heart transplant was first performed in the 70's, but it was not until the 80's that heart transplantation was carried out more routinely (Bounce et al., 2007). The overall number of paediatric heart transplants has remained stable over the last 15 years at about 400 procedures per year internationally (Bounce et al., 2007). In Canada, on average 40 paediatric heart transplants are performed annually (Canadian Institute for Health Information, 2010). The heart transplant program at the Hospital for Sick Children (HSC) began in 1990. Healthcare professionals have been performing 16 – 20 transplants every year, maintaining a cardiac centre that is one of the busiest in the world. On average 55% of recipients followed at the HSC transplant program are male, which is comparable to international centers (Canadian Institute for Health Information, 2010). Two thirds of children present to clinic with symptoms of cardiomyopathy and one quarter of children are diagnosed with congenital heart disease (Canadian Institute for Health Information, 2010).

Improvement in immunosuppressive therapy and the management of transplant related complications have significantly enhanced the survival of individuals (Ross et al., 2005). Approximately 70% of children and adolescents following a paediatric heart transplant will reach young adulthood (Ross et al., 2005). On their pathway to young adulthood, transplant recipients

will have to undergo multiple medical interventions in order to manage and prevent transplant related adverse effects (Ross et al., 2005). Complications may include: rejection, serious infection, hypertension, cancer, graft coronary artery disease, graft failure with subsequent need for heart re-transplant and renal dysfunction with potential need for renal transplant (Ross et al., 2005). In hospitals a multidisciplinary team composed of nursing transplant specialists, social workers, pharmacists, researchers, and transplant physicians are committed to preventing and managing adverse outcomes. Additionally, the healthcare team monitors for side effects of medications, which can frequently lead to facial swelling, acne, and weight gain. Often, female adolescent transplant recipients cite cosmetic reasons for discontinuing their medication (Meyers, Thomson, & Weiland, 1996). Studies have suggested that children who received a vital organ transplant have more behavioural problems and less social competence than healthy peers (Uzar et al., 1992). Physical symptoms and limitations are a potential cause for increased rates of depression and anxiety (Glazer, Emery, Frid, & Banyasz, 2002; DiMatteo, Lepperd, & Croghan, 2000; Katon & Ciechanowski, 2002). Children with physical restrictions have fewer social interactions, potentially decreasing the development of peer-relationships, which might have long-term consequences for their social development (Meijer, Sinneman, Bijstra, Mellenbergh, & Wolters, 2000).

Most adolescents are faced with the developmental tasks of becoming independent from their families, developing a sense of themselves that incorporates sexual identity, romantic relationships and finding employment. In addition to becoming a young adult however, transplant recipients are coping with a life-threatening disease and may struggle to become responsible for their medical care (Cupples et al., 2006). Taking on added responsibilities is especially relevant when individuals transition from a paediatric hospital to an adult healthcare

facility. In Canada, children who have received a heart transplant are cared for in a paediatric hospital until the age of 18. Frequently, the healthcare team caring for the child or adolescent has established trust and a familiarity with personal and condition specific needs (Paone, Wigle, & Saewyc, 2006; Kaufman, 2006). At age 18, the individual's care is transferred to an adult healthcare facility. Transplant teams have started to recognize that transition from a paediatric to an adult hospital is a complex process that goes far beyond the transfer of care (McCurdy et al., 2006).

Clinicians are aware that transition is an ongoing process and must be youth-focused to meet the needs of the adolescent. Up to 50% of young recipients suffer from neurological complications, 27% of all heart recipients show behavioural problems and 29% of individuals have reported clinically significant psychological problems (Weil, Rodgers, & Rubovits, 2006). Transition, therefore, needs to occur at the adolescent's and family's pace, taking into consideration medical stability, cognitive development and their personal goals (Paone, Wigle, & Saewyc, 2006; Kaufman, 2006). The young recipient who is intellectually impaired or who struggles to master daily living skills faces more challenges during the transitional process than other young adults (Kaufman, 1995). Young adults who have transferred to an adult care facility report that they know very little about their new health center and are unfamiliar with the members of the health care team (McCurdy et al., 2006). Healthcare professionals' ultimate goal for the young adult with ongoing healthcare needs is to reach his or her attainable level of independence and self-sufficiency (Kaufman, 1995).

Problem statement & study purpose

Three decades of performing life-saving transplant procedures has resulted in enough children with a heart transplant to reach young adulthood, thus creating a large group of individuals that have not been well researched and necessitate further exploration. Regrettably, in Canada, standards of care and services in adult health care facilities are designed for the ‘typical’ heart transplant recipient. Practice is based on research where 70% of ‘typical’ study participants are male and on average 55 years old. These same standards guide the provision of care for young adults. Apart from the obvious difference in age and gender distribution, young adult transplant recipients disease trajectory is arguably very distinct from other transplant recipients. The question raised was, are current standard approaches to adult care appropriate in the management of young adults? Hence, it was critical to explore young adults’ circumstances of existence and their struggles with competing social environments.

Theoretical orientation

This research project applied Pierre Bourdieu’s theoretical concepts of habitus, field and capital, to conceptualize and engage with empirical knowledge production about young adults who had received a heart transplant during childhood. His theory was ideal in conceptually linking physiological, psychological, social, and cultural dimensions of young adult heart transplant recipients’ realities and provided a structure for thinking about and empirically analyzing the social world. A particular contribution of this study was to advance thinking about the multi-component nature of being a young adult transplant recipient by examining how young adults resituate themselves within various fields of health service consumption; how they re-

inhabited their bodily practices of self-care; and how they were inculcated with new cultural capital as patients in an adult healthcare facility.

Methods

Using visual methodology, focused open-ended interviews were conducted with young adults who have had a heart transplant during childhood. Bourdieu's work provided a theoretical framework to investigate transplant recipients' identities and social re-positioning in relation to dominant discourses of organ transplant and shifting relationships with health services providers. The study explored how young adults resituate themselves within a new field of health service consumption. How they re-inhabited their bodily practices of self-care. How they were inculcated with new cultural capital as patients in an adult healthcare facility. This study involved an iterative process, to identify recipients' encounters and new compositions in relation with others, in order to answer the research objective.

Results of this study enhances the understanding of what it is like for young adults, who received a heart transplant during childhood, to live with a heart transplant. Such findings can potentially lead to improvement in ongoing care and services for young adults who require a lifetime of care. At the same time, it will allow nurses to better prepare and counsel young individuals who are preparing for a heart transplant.

An outline of the chapters

This dissertation sets out an argument in seven chapters. The intent is to explore the lives of young adults who have received a heart transplant during childhood and have recently transitioned to an adult healthcare facility. Chapter two explores four bodies of empirical research that are relevant to the research study and will be reviewed in turn. In chapter three I

describe the theoretical perspective that I used to situate young adult transplant recipients within the social world. In chapter four I outline the qualitative visual method I used to explore young adult transplant recipients' life circumstances. Chapter five represent the results of the study that have been divided into two parts. Together they fulfill the study purpose and provide interpretive results that draw on the study's theoretical underpinning. Findings of this study are then taken up in more detail in chapter six where I discuss the results of this study. I provide a conclusion to my work in chapter seven with a focus on theoretical, practical, and research contributions.

CHAPTER 2: THE LITERATURE AND STATEMENT OF THE PROBLEM

Introduction

There is a vast amount of literature on cardiac transplantation, but very little of it directly touches on the problem that motivated this study. The findings for this literature review were generated by searching MedLine (1966-present), CINAHL, IBSS – International Bibliography of the Social Sciences, PsychInfo, Google Scholar, and reference lists of relevant articles from May 17, 2010 until October 1, 2010. A more recent search was conducted in order to capture studies that were published since the initial literature review. Searches were refined for various combinations of key words and phrases: organ/heart transplant, physiological outcomes, complications, clinical improvement, mortality, cosmetic changes, reproductive health, puberty, fertility, psychological outcomes, social outcomes, adolescent, depression, social isolation, school re-entry, education, adjustment, family conflict, parent, quality of life, satisfaction happiness, functional status, health status, well-being, transitional care, continuity of care and chronic care. The literature reviewed here pertains to heart transplantation, and includes relevant work on other forms of transplantation, severe illness, identity disruption as well as studies pertaining to emotional and psychological adjustment and adults' perception of being a recipient. Results included peer-reviewed scholarly articles, research reports, dissertations, conference papers, books, newspaper articles and websites. This literature review was conducted with the goal of methodological inclusion and tolerance, in order to generate a broader understanding of the transplant experience of young adults (Sandelowski et al., 2007). The improved success of heart transplant offers children and adolescents a chance to extend life into young adulthood,

which has created a group of individuals that have not been well researched. Healthcare professionals will not be able to understand what it is like to be a young adult who has grown up with a heart transplant through synthesizing current research conducted on paediatric and adult transplant recipients. Although limited research exists that explores the lives of young adults who have received a heart transplant during childhood, four bodies of empirical research are relevant to the research study and will be reviewed in turn. First, I provide an overview of research that explores the role of physiological, psychological and social factors in the clinical course of paediatric heart transplant recipients. Second, I examine recipients' need for lifelong care and their transition from a paediatric to an adult healthcare facility. Third, I will highlight the few existing publications on young adults who have received a heart transplant during childhood. Fourth, I present a comprehensive review of research that examines quality of life (QoL) in adult heart transplant recipients and how heart transplant impacts adults' perception of being a recipient. Throughout this literature review, I will identify and reflect on overall theoretical and methodological shortcomings.

I. Clinical course of paediatric transplant recipients: review of physiological, psychological and social outcomes.

Physiological outcomes

Early mortality rates after paediatric heart transplant have been decreasing since the 1980's and recipients enjoy good short-term survival (Schowengerdt, 2006). Acute organ rejection remains one of the main complications within the first year following transplant (Alkhalidi et al., 2006). Approximately 30 to 40% of paediatric heart transplant recipients

experience episodes of rejection within their first year (Alkhalidi et al., 2006). Acute rejection remains one of the most common causes for death within the first years of transplantation among children and adolescents (Russo & Weber, 2004). In most instances, rejection occurs without any significant clinical symptoms and can therefore only be diagnosed through myocardial biopsies (Alkhalidi et al., 2006). The frequency of such biopsies has been much debated among health care professionals and schedules are institution specific (Chin et al., 2000, Leonard et al., 2000). Depending on the time following transplant and the age of the child, biopsies are performed every few weeks when there are signs of rejection and will be extended to every 4 to 6 months in stable individuals (Luikart, 2001).

Late survival continues to be a challenge largely related to the development and progression of long term complications (Schowengerdt, 2006). Pediatric heart transplant recipients who have survived the first year have a median survival of 15 years (Boucek et al., 2007). The report of the International Society of Heart and Lung Transplantation (ISHLT), which was published by Boucek et al. (2007), highlights that cardiac allograft vasculopathy (CAV) and renal failure remain the two major late-term complications following paediatric heart transplantation.

Cardiac vasculopathy leads to progressive graft dysfunction and has been reported in 31% of paediatric long term survivors (Ross et al., 2006). Graft dysfunction also carries an increased risk for dysrhythmia and a potential of sudden death (Schowengerdt, 2006). Additionally, 14% of paediatric recipients experience episodes of atrial tachycardia and 5.2% of individuals will need to have a permanent pacemaker implanted in order to treat their arrhythmia (Collins et al., 2002). Registry data demonstrates that CAV significantly contributes to late morbidity and mortality. Due to the lack of significant treatment options (Boucek et al., 2007;

Schowengerdt, 2006; Musci et al., 1998; Razzouk et al., 1998; Mulla et al., 2001) 15% of recipients undergo cardiac re-transplant (Ross et al., 2006). Survival after re-transplant, however, is poorer than after a first heart transplant (Chin, 2006).

Heart transplant recipients are exposed to life-long immunosuppressive drug therapy, some of which are potentially nephrotoxic and can lead to serious progressive renal failure. Renal dysfunction might be present immediately after transplant due to chronic low cardiac output (Schowengerdt, 2006). Nevertheless, ongoing and slowly progressing renal failure is common with long term use of immunosuppressive therapy (Schowengerdt, 2006) and 8% of pediatric long term survivors will require a renal transplant (Ross et al., 2006). Careful management to avoid excessive exposure to treatment with nephrotoxic drugs is warranted. Currently, clinicians are in the process of establishing more effective methods to identify individuals who are at risk for developing serious renal disease.

Studies conducted on long term survivors of paediatric heart transplants confirmed that 69% received medication for hypertension, 44% developed serious infections, and 23% of recipients developed neoplasms (Ross et al., 2006). The development of neoplasms has been well recognized as a serious complication in additional studies (Gambino et al., 2007; Boucek et al., 2006; Baley et al., 1993; Penn, 1998). Hyperlipidemia is common following transplantation due to ongoing treatment with immunosuppressive drugs (Schowengerdt, 2006). Fifty percent of paediatric heart transplant recipients suffer from chronic respiratory conditions, which frequently require individuals to be followed by a respirologist (Biju et al., 2007).

Impaired growth rate has been well documented in children and youth prior to as well as following paediatric heart transplant (Chinnock et al., 1998). Chronic heart failure and ongoing immunosuppressant therapy are the main reasons for decreased growth in the paediatric

population (Alkahldi et al., 2006). Several studies have demonstrated, though, that improved medical therapy and longer steroid free periods have allowed 75% of recipients to achieve normal growth, including appropriate development of muscle mass in proportion to body growth (Bernstein et al., 1992; Zales et al., 1994).

As young transplant recipients grow and mature, there are limited data to guide decision-making for contraception. Different contraceptive methods are available for transplant recipients with various advantages and disadvantages. A combined hormonal oral contraceptive pill, though very effective, might present serious complications such as thromboembolic and cardiovascular disease (Sucato & Murray, 2003). Cardiovascular disease among heart transplant recipients, which is found in 40% of patients 2 to 5 years following transplant, is a contraindication for the use of oral contraceptive pills (Morel et al., 1991). Hypertension, which is a side effect of immunosuppressant use, might represent another contraindication for the use of oral contraceptives. The Consensus Conference of Reproductive Issues and Transplantation (Shaben, 1993) reported, “while data are limited there is no information to suggest that oestrogen/progesterone is associated with adverse consequences in transplant patients when hypertension is well controlled.” However, combined oral contraceptive pills can interact with many medications and closer observation of immunosuppressant medication concentration is needed (Sucato & Murray, 2003).

Alternatively, recipients might be able to use progestine only medication, which have fewer drug interactions. These drugs, however, are less effective than combined hormonal oral contraceptives and are not always recommended as first line therapy. Intrauterine devices are rarely used in adolescents because of concerns of pelvic infection. They remain relatively

contraindicated for use by transplant recipients because of their immunocompromised state and the concern of infection (Sucato & Murray, 2003).

Barrier contraception provides the safest options for transplant patients (Winkler et al., 1993; Henning et al., 1988; Morel et al., 1991). Condoms decrease the risk of sexually transmitted disease, but are rarely used as the sole contraceptive option in adolescents due to the high failure rate (Sucato et al., 2003). For women younger than 20 years of age contraceptive failure rate of condoms typically range between 10% to 53% during their first year (Spona et al., 1996). Diaphragms and cervical caps are rarely used by adolescents and have unacceptably high failure rates (Sucato & Murray, 2003). There are no known contraindications for the use of emergency contraception (Sucato & Gold, 2002), with progestine only regime being the preferred method because of its improved effectiveness and lower incidence of side effects (Sucato & Murray, 2003).

When transplant recipients become of childbearing age it is necessary to discuss pregnancy, its potential risks and complications for the mother as well as the baby, effects of immunosuppressive therapy, and the effects of pregnancy on the transplanted heart (Mastrobattista & Katz, 2004; Armeti et al., 2003). Pregnancy is typically not recommended within the first year following transplant, since there is a greater risk for organ rejection and individuals require higher doses of immunosuppression. The National Transplantation Pregnancy Registry (NTPR), which was established in 1991, collects information on female transplant recipients who have had a pregnancy and male transplant recipients who have fathered a child. Data is collected via telephone interviews and questionnaires and medical records. Limited information exists about pregnancy among heart transplant recipients, but there is an overall consensus that in individuals with stable immunosuppression and good graft function, pregnancy

is well tolerated, with most pregnancies having successful outcomes for newborn and mother (Armenti & Katz, 2003). These recommendations seem very promising for recipients who would like to become mothers; nevertheless, healthcare professionals agree that heart transplant recipients who are pregnant require vigilant observation of their medical treatment in order to prevent graft rejection (Mastorbattista & Katz, 2004). Individuals are at risk for preterm birth, foetal growth restriction, with increased risk for infection and pre-eclampsia in the mother (Mastorbattista & Katz, 2003). Additionally, transplant recipients who are becoming parents need to consider their own life expectancy following transplant and alternative arrangements need to be made for ongoing care for the child in the long term. In general, reports have not distinguished between pregnancy in individuals who received their transplant as an adult and pregnancy of adolescent transplant recipients.

Psychological outcomes

A recent review of psychological functioning and adjustment following organ transplant identified that paediatric heart transplant recipients are the least studied group of recipients (Fine et al., 2004), which might be related to the relative small number of recipients in individual centers. Psychological evaluation of paediatric heart and heart-lung transplant recipients confirmed that individuals had significantly higher behavioural and psychological distress than comparable healthy peers. A longitudinal study exploring psychological functioning after transplant, demonstrated that the majority of study participants had the capacity for healthy psychological functioning; nevertheless, follow-up is required since >25% of recipients experienced emotional adjustment difficulties (DeMaso et al. 2004). Findings show that psychological functioning improved over time; however, a number of recipients had ongoing

psychological troubles (Wray, 2004, 2006). From 104 adolescent organ transplant recipients more than 16% of study recipients met all the criteria for post-traumatic stress syndrome, with an additional 14.4% meeting two to three of the symptoms criteria (Mintzer et al., 2005). By using previously validated measures of behaviour and depression in paediatric heart and heart-lung transplantation recipients, researchers reported that a number of study participants experienced psychological difficulties following the transplant (Wray & Radley-Smith, 2007).

Social outcomes

Outcome research has also focused on school re-entry of paediatric heart transplant recipients. In the United Kingdom, 81 children were assessed for their academic performance and behaviours at school, at specific intervals following their transplant (Wray et al., 2001). Overall, study participants cognitive and academic attainment was within a normal range, though several individuals displayed significantly lower levels of performance in comparison to other children in their school. Six percent of study participants displayed behavioural problems at 6 months after the transplant. Behavioural problems subsequently increased to 29% after three years and remained high at 27% five years after the transplant. Individuals with a history of congenital heart disease had more academic and behavioural problems than children with a history of cardiomyopathy (Wray et al., 2001). Wray et al. (2001) concluded that a significant number of successful paediatric heart transplant recipients experience behavioural problems when returning to school, with numerous participants struggling with behavioural problems several years after the transplant.

A study conducted in the US implemented standardized measures to evaluate cognitive, academic and behavioural function in individuals who underwent a paediatric cardiothoracic

transplant and compared participants' scores to same age normative samples (Broising et al., 2006). Results for cognitive functioning confirmed that typically individuals fell within the low average to average score. Analysis of individual scores, however, confirmed that 54% of study participants fell within the average range of intelligence and of those 46% showed significant cognitive delays. Similar results were found for academic achievement scores, with mean scores not being significantly different to normative scores. Individual analysis of findings highlight that 78% fell within the average range for reading and spelling, and 57% scored average for math. Of note, 62% of study participants were enrolled in special education programs at their schools. Additionally, 27% of mothers and 11% of fathers reported that their child or teenager experiences some form of behavioural problems being expressed through episodes of anxiety, depression or aggression. The research team highlighted that the existence of cognitive and academic concerns was also related to socioeconomic status, whereas the presence of behavioural problems did not show any relation with socioeconomic status (Broising et al., 2006).

Few studies have explored the potential link between socioeconomic racialized social position and successful outcome in paediatric heart transplant recipients. There is evidence from the United States that adverse social circumstances (Singh et al., 2009) and being African American (Mahle et al., 2005) can be linked to worse outcomes following a transplant. Researchers reviewed transplant outcomes of 135 children who had their first paediatric heart transplant at Children's Hospital in Boston between 1991 and 2005. The results of the study suggest that in paediatric heart transplant recipient's, lower socioeconomic position may be an independent risk factor for graft failure (Singh et al., 2009). Mahle et al. (2005) analyzed data from United Network for Organ Sharing to explore the relationship between socioeconomic position and race on transplant outcomes. The study demonstrates that black paediatric heart

transplant recipients had a significantly lower graft survival rate compared with other racial groups, 51% versus 69%. There have been several other reports that demonstrate a higher graft rejection after paediatric heart transplant among black recipients (Chin et al., 2004; Pahl et al., 2001). In comparison, research conducted in a cardiac transplant center in the United Kingdom (UK) included 78 children who underwent a heart transplant between 2001 and 2005. The team emphasized in their findings that adverse socioeconomic positions were not related to increased graft rejection and up to this point no child or adolescent had been declined for a heart transplant based on psychological or socio-economic grounds in the UK (Brown et al., 2009).

As paediatric transplant recipients become more responsible for their care, non-adherence with medication regimes, clinical appointments and lifestyle modifications have been described as a concern following paediatric organ transplantation (Lawrence et al., 2008). Research has demonstrated that non-adherence is directly linked to increased morbidity and mortality in transplant recipients (Dobbels et al., 2005). Approximately one third of heart transplant recipients do not adhere to medical recommendations (Casey et al., 2000). Young transplant recipients struggle with rejection by friends and peers, independence from parents and issues of establishing intimacy and sexual relationships (Kaufman et al., 2006).

Healthcare professionals and parents of children with chronic conditions previously assumed that adolescents dealing with an ongoing medical condition are less likely to be involved in high-risk behaviours and might receive less information about potential negative consequences. Several studies have explored and identified high-risk behaviours in adolescents with chronic conditions. Findings suggest, however, that individuals are as likely or more likely to engage in the use of illegal substances (DeMaso et al., 1995; Anthony et al., 2009; Suris & Parera, 2005), have sexual relationships (DeMaso et al., 1995; Anthony et al., 2009; Graetz et al.,

2000;), practice unprotected sex (DeMaso et al., 1995; Anthony et al., 2009; Crockett et al., 2005) and demonstrate abnormal eating habits (Houtzager et al., 2004) when compared to healthy peers. A review of a Swiss national health assessment of 7548 adolescents, of which 760 individuals identified themselves as having a chronic health condition and 6493 study participants stated to be without health concerns (four percent of data was discarded because of incomplete data), confirmed that adolescents with chronic illnesses are more likely to engage in health risk behaviours (Suris et al. 2008). The assumption that adolescents who are dealing with chronic medical conditions are less likely to engage in high risk behaviour has not been supported by current research and therefore concerns associated with high risk behaviours need to be addressed with young transplant recipients.

General health risk behaviours like illicit drug use, smoking, drinking and unprotected sex are associated with the general health status of adolescents (Simpson et al., 2006). Family and societal norms frequently influence adolescents' understandings of what might be understood as normative behaviour, in comparison to risky behaviour (Valencia, 2000). A psychological model of risk behaviour proposed by Jessor (1991) states that adolescents' risk behaviour could be a function of normal development. Activities like smoking, drinking and sexual behaviour might be associated with finding acceptance within a group and establish a sense of maturity. Risk behaviours can further help adolescents establish autonomy from parents or cope with stress and can be seen as normal adolescent behaviour (Jessor, 1991). Any negative risk behaviour, however, might be interpreted as unsafe if the person is not aware of its potential physical and emotional consequences of their behaviour (Valencia, 2000). Negative risk behaviour can most certainly adversely affect or endanger the individuals' health, development and ultimately transition into young adulthood.

As outlined in this literature review, improved success of heart transplant offers children and adolescents a chance to extend life into young adulthood and there is a growing body of research that examines physiological, psychological and social outcomes. The results of psychological functioning (Wray, 2004, 2005; Libman Mintzer et al. 2005; Wray & Radley-Smith, 2007) and social behaviours (Wray, 2003; Singh et al., 2009; Mahle et al. 2005; Brown et al., 2009) suggest that many paediatric transplant recipients are performing poorly. Frequently, studies focus on individual's participation in social groups, physical activity, performance at school and their relationships with peers. Due to the nature of cardiac disease, however, many children who are waiting for a heart transplant have severe physical restrictions, which continue to be the case up to several months following transplantation. These physical restrictions might be due to medical reasons or parental anxiety and frequently hinder individuals to actively participate in physical activities or socialize with various people.

All the children miss school and for some this can amount to months of education, which has been observed in decreased academic performance (Brosing et al., 2006). In previously conducted research assessing psychological function and social development, factors such as physical limitations, living with a progressive terminal condition, school absenteeism and the lack of social interaction have not been taken into account. Researchers have not monitored long term outcomes of the reported psychological and social changes. Additionally, assessment of the recipients' behaviour is frequently reported by the parents, and it is conceivable that parents' mental and emotional state might influence individuals reporting of their child's behaviour.

II. Transition from a paediatric to an adult healthcare facility.

As transplant recipients become young adults they transition from a paediatric hospital to an adult health care facility. Transition is defined as “ the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (American Academy of Paediatrics, 1996). Living with a chronic disease entails that transplant recipients’ healthcare needs change and individuals constantly need to adjust to their disease sequelae (American Academy of Paediatrics, 1996). Health care professionals develop long-standing relationships with the transplant recipient and their family, often becoming more bonded through various events in the recipients’ course of care (American Academy of Paediatrics, 1996).

In order to provide the best possible care for individuals in Toronto, heart transplant recipients are transferred from paediatric to adult care at age 18. Few studies have specifically explored young heart transplant recipients’ perceptions of the process of transition from paediatric to adult transplant care. The goal of transition is to provide continued age appropriate care for transplant recipients (McCurdy et al., 2006). McCurdy et al., (2006) conducted a qualitative case study approach highlighting that transition for heart transplant recipients can often be very difficult and traumatic. Remorino & Taylor (2006) reported that kidney transplant recipients who participated in a transition program were no more satisfied overall than recipients who were not enrolled in the program (Remorino & Taylor, 2006). Transition is seen as extremely challenging and services cannot be targeted only for high-risk patients (Remorino & Taylor, 2006).

Research reports suggest enhanced outcomes for adolescent patients with increased and individual attention to transitional care (Anthony et al., 2009). By considering the current and

carefully assessed developmental state of recipients the frustration experienced during the transition process could be reduced (Kaufman, 2006). Researchers emphasize that it is important for healthcare professionals to keep in mind that development does not stop with transition of care (Kaufman, 2006). Challenges during this time include “abrupt transfer, insufficient communication between paediatric and adult specialty providers and becoming lost to follow-up” (Stabile et al., 2005). Recipients can be guarded when accessing the adult healthcare system because it is very different to what they have been used to. It frequently takes a significant amount of time to develop new trusting relationships (Harden & Nadine, 2006). Anthony (2009) highlights in order to facilitate transition there needs to be better understanding of the experiences and perceptions of both the adolescent heart transplant recipients and their parents. Specific issues such as: “a) adolescents’ disinterest and apathy regarding transition to adult care versus parental anxiety about their child’s eventual departure from the paediatric transplant center, b) perceived differences in paediatric versus adult care, c) identification of strategies described as helpful in facilitating transition” (p. 614) need to be addressed in order to advance the state of transitional care (Anthony, 2009).

Researchers have highlighted paediatric transplant recipients’ non-adherence with medication regimes and struggle with lifestyle modifications (Lauwrence, 2008). Findings show participants struggle with rejection by friends, independence from parents, intimacy and sexual behaviour (Kaufman, 2006) and demonstrate high risk-behaviours (DeMaso et al., 1995; Anthony et al., 2009; Suris, 2008). As Kaufman et al. (2008) conclude in their study, individuals who incorporated their transplant into their lives, matured well, and became independent individuals, were more able to follow recommendations from their healthcare team. No study to date has investigated how young adults who have received a paediatric heart transplant

incorporate their transplanted heart into their sense of self. Previously conducted research on paediatric heart transplant recipients has focused on physiological, psychological and social outcomes following the procedure and did not focus on explaining how individuals incorporate their transplant into their daily life. At the time of this literature review no additional publications were found from social scientists who engaged with the phenomenon of paediatric heart transplantation.

III. Young adults who have received a paediatric heart transplant.

To date, only two studies have been conducted that reviewed outcomes of young adults who received a paediatric heart transplant. First, Ross et al. (2005) retrospectively reviewed 52 charts of children who received a heart transplant under the age of 18. At the time of the study most individuals were between 15 and 20 years post transplant, with one individual being 26 years. Although the team reported that late complications post transplant are frequent and that individuals overall adapted very well to their new situations (Ross et al., 2005), quality of life after transplant was not addressed. Second, Petroski et al. (2009) conducted a prospective study including 23 young adults (65% men, 91% white) who had a heart transplant during childhood and who have lived more than 10 years following the procedure. At the time of the study, participants were between 2 and 9 years old when they received their heart transplant and were 11 to 22 years following the procedure. Clinical data was collected from medical records and the study included the use of the SF36 short assessment form, in order to assess quality of life. The report highlighted that individuals' perceptions of their mental and physical health were similar to those of the general population. Of note, compared with normative sample of adolescents, individuals had significant lower quality of life scores for social, psychological and school

function (Weil, Rogers, & Rubovits, 2006).

The studies conducted by Ross et al. (2005) and Petroski et al. (2009) explored young adults disease trajectory of living with a heart transplant by applying chart audits and/or using quantitative self-reported measurement tools. It is likely that post-positivist approaches in exploring the experience of living with a heart transplant might not capture the depth of the event. Furthermore, the study by Petroski et al. (2009) uses self-reported questionnaires to assess individuals' quality of life. It is conceivable that participants could present themselves as psychologically more stable in order to show their gratitude for having received a heart transplant, aiming to live up to healthcare professionals, family members, and donor families expectations.

In contrast, research conducted in Canada by Ross et al. (2010) with adult heart recipients using qualitative research methods, demonstrated that 88% of heart transplant patients experienced pervasive post-transplant distress. These findings are in stark contrast to other reports that used quantitative measures and claimed that, after heart transplant, approximately 33% of all recipients report emotional problems, which are not attributable to medication or patho-physiological changes (Dew et al., 2005). Ross et al. (2010) highlighted that their higher numbers of distressed patients might have been under-reported if assessed by standard quality of life questionnaires. To that end, no study to date has used qualitative research methods to explore what it is like to be a young adult who has received a heart transplant during childhood, and how recipients deal with the challenges of growing up with a life threatening disease. Hence, the use of qualitative research methods is best suited to critically explore young adults' experience of living with a heart transplant.

IV. Adult transplant recipients.

A large number of qualitative studies on ‘typical’ adult heart transplant recipients show improvement in Quality of Life (QoL), but poor return to work (approximately 45%), as well as high levels of general anxiety and distress (Dew et al., 2005; Paris & White-Williams, 2005; Paris et al., 1993; Tyler et al., 2006). A recent review, incorporating nearly 150 studies, confirms that “depressive and anxiety-related disorders and associated distress are common post transplant” (Dew et al., 2005, p. 1215) and that such symptoms are not confined to the initial stages of recovery, but may appear or be exacerbated at any time (Dew & DiMarini, 2005).

One longitudinal QoL study followed 156 adult patients over a four-year period post-transplant using the depression and anxiety subscales of the Symptom Checklist 90 (Dew et al., 2005). Twenty-one percent experienced “high, clinically significant distress at all times.” Another 12% showed “high distress over several years with low distress only at final assessment,” while the remaining participants experienced low or fluctuating levels of distress for the duration of the study. Approximately one-third of heart recipients, therefore, were found to experience substantial, sustained distress.

Ross et al. (2010) used a phenomenologically informed audiovisual method to explore the nature of distress in heart transplant recipients. The research participants included 27 medically stable heart transplant recipients who had no prior treatment for psychological or social issues. The team reported that 88% of study participants displayed distress during the interview (Ross et al., 2010). Most commonly, verbal or bodily indications of distress surrounded discussion of the donor, donor family, writing to the donor’s family and being the beneficiary of the “gift of life”. Fifty two percent of study participants demonstrated pervasive

distress throughout the interview. This distress was manifested as anger, sadness and flat affect, regardless of the discussion content (Ross et al., 2010). In this particular group, distress was deemed significant enough by the research team to raise clinical concerns regarding the need for treatment and support. In addition, one study participant was subsequently diagnosed with post-traumatic stress disorder after seeking clinical care within one month after completion of the study (Ross et al., 2010).

In the transplant literature ‘distress’ refers to psychiatric diagnosis such as depression, anxiety and psychosis (Abbott, Agodoa, & Malley, 2003; Brosig & Woidera, 1993; Bunzel, Wollenek, & Grundbock, 1990; Bunzel et al., 2005; Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa, 2003; Laederach-Hofmann, Begre, & Bunzel, 2002; Salvucci, 2004; Triffaux, Demoulin, & Limet, 2002). Case studies of heart recipients report otherwise inexplicable psychiatric conditions post-transplant, including “night-time anxiety, feelings of suffocation” (Brosig & Woidera, 1993, “organ related fantasies” (Laederach-Hofmann et al., 2002), “delirium” (Triffaux et al., 2002), and “psychosomatic hyperventilation syndrome” (Bunzel et al., 1990). Psychoanalytic studies of recipients report overpowering feelings of gratitude to the donor family, guilt over the donor’s death, denial, and mourning of their own lost organ (Kaba, Thompson, & Burnard, 2005; Sanner, 2003). Some investigators have concluded that negative psychological responses may impact the physiological integration of the graft, and consequently the health of recipients (Dew & DiMartini, 2005; Abbott et al., 2003). These responses include non-compliance resulting in organ rejection as well as psychosomatic symptoms in which psychological distress is manifested in physical symptoms (Dew & DiMartini, 2005; Bunzel et al., 1990; Salvucci, 2004).

In contrast, other psychosocial/psychiatric research shows that many heart graft recipients

believe they have taken on characteristics of their donors (Pearsall, 2001; Pearsall, Schwartz, & Russek, 2002; Sanner 2003, Brosig & Woidera, 1993; Burner, 1994; Inspector, Kutz, & David, 2004). These findings, although concordant with first person accounts of popular media portrayals, have not been widely accepted by transplant professionals (Potts, 1998; Scanner, 2005; Lock, 1995; Sanner, 2001). One Israeli study of 35 male heart recipients employed five assessment tools including SCL-90 (revised) to investigate recipients' attitudes towards the graft and the donor. Although the Heart Image Questionnaire (no psychometric properties reported) confirmed, "all recipients possessed a scientific knowledge of the anatomy and physiological significance of the heart," almost 50% of the recipients "had an overt or covert notion of potentially acquiring some of the donor's personality characteristics along with the heart" (Inspector et al., 2004). In a study of 47 Viennese heart recipients, 21% of respondents said their personality had changed post operatively, attributing this to either the trauma of nearly dying (15%) or the grafted heart itself (6%) (Bunzel, Schmid-Mohl, Grundbock, & Wollenek, 1992). The remaining 79% showed massive defense and denial reactions, mainly by rapidly changing the subject or making the question ridiculous. The investigators concluded that the problem with incorporating a transplanted heart might be related to the idea that the heart houses feelings and forms personality (Bunzel et al., 1992).

Few researchers have explicitly connected organ recipients' experiences and cultural views about transplantation to the notion of embodiment. One sociological study, consisting of interviews with 19 families who consented to donate a relative's organs, found that conceptions of embodiment – i.e. whether you have a body, or you are a body – varied among the sample, and in some cases had affected the decision to donate (Haddow, 2005). Some anthropologists have investigated broader cultural attitudes about the body and the meaning of transplantation.

Joralemon (1995) frames popular discourse about organ transplantation and “procurement strategies” in terms of two familiar but opposed American values, altruism and individual rights (Joralemon, 1995). He argues that, as much as cyclosporine suppresses the body’s instinct to attack foreign tissue, widespread intuitions about the inseparability of body and personal identity must be dampened in order for organ transplantation to attain social approval. The dominant medical rhetoric regards the procedure as an exchange of “spare parts,” which recipients are encouraged to reify and disassociate from their donors (Sharp, 1995; Waldby, 2002; Sanner, 2001). Simultaneously, large-scale awareness campaigns promote organ donation by employing gift metaphors and appealing to beliefs about the deceased donor “living on” in recipients. However, such attitudes toward the meaning of the human body appear to conflict (Potts, 1998; Sharp, 1995), and some critics have begun to explore the unanticipated distress such corporeal generosity may entail (Diprose, 2002; Hird, 2007).

American anthropologist Lesley Sharp (1995) provides a comprehensive description of adult transplant recipients’ views on embodiment. She conducted in-depth interviews with 26 heart, lung, and liver transplant recipients in relation to the medical view of the body, cultural attitudes toward transplantation, and the “gift of life” slogan used in donor campaigns. Some recipients reported seeking out their donor’s families and attempting to form relationships with them, and vice versa, despite efforts of professionals to keep both anonymous; some had actively integrated the real or imagined personality of the donor into their post-transplant identity; and some assumed an identity centered on their labels as “a heart” or “a liver”. Recipients who personalized their organs or felt a kinship with their donors’ families were chastised by physicians for harbouring “unscientific” attitudes. Sharp (1995) explained that seemingly unusual behaviours might in fact be a logical response to unusual conditions.

The research project presented in the following chapters was an exploratory study and the review of previous work in adult transplant recipients was not discussed in order to hypothesize similar findings in young adults following a paediatric heart transplant as this might pose an erroneous stance. It was deemed conceivable that growing up with a transplanted heart sets up a very different ‘transformatory’ experience for these individuals. To address this critical gap in knowledge, the research was guided by the work of Pierre Bourdieu in order to explore the meanings and perceptions of recipients’ experience following a heart transplant.

Chapter Summary

Young adults who have received a heart transplant in childhood experience multiple life sustaining procedures. As survival and longevity increase, it has become clear that transplant recipients may experience negative physiological, cognitive, psychological and social sequelae. With heart transplant offering individuals a chance to extend life into young adulthood, recipients need lifelong care and will transition from a paediatric to an adult healthcare facility. Only two studies have been conducted on this particular group of young adults who have had a heart transplant in childhood. The projects incorporated self-reported questionnaires and chart audits to gain a better understanding of young adults. Findings show that individuals adapt well to their situation and report mental and physical health similar to the general population. Previously reported physical, social, and psychological concerns in children and adolescent are no longer present or not captured in young adults using quantitative research methods. Parallel, research conducted on adult transplant recipients repeatedly identifies individuals struggles associated with their heart transplant. The range of evidence supports that receiving a heart transplant leads to physiological and psychological changes. Health research in adults has

revealed the challenges of living with a transplanted heart and has highlighted the prevalence of emotional distress.

CHAPTER 3: THEORETICAL PERSPECTIVE

Introduction

This research project drew on Bourdieu's theory of practice to conceptualize and engage with empirical knowledge production about young adults who have received a heart transplant in childhood. A particular contribution of this study was to advance thinking about the multi-faceted social positionings occupied by young adult transplant recipients by examining the impact of a shift from the field of paediatric health care to that of adult care.

In this section of the study, I describe the theoretical perspective that I used to situate young adult transplant recipients within the social world. I provide a sketch of an event that impacted my thinking about organ transplantation and ultimately led me to the work of Pierre Bourdieu. I outline Bourdieu's concept of habitus and its interconnection with field and capital, which provided a framework for conceptualizing the social world and guidance for empirical research. This includes a review of events that surrounded Bourdieu's life and impacted his thinking, followed by a clear definition and current uses of this concept in health sciences. I discuss the application of Bourdieu's concepts in research and conclude with a critical analysis of potential limitations.

Being reflexive of events that impacted my thinking

I first became interested in the work of Bourdieu while working as a research associate on a study that examined the process of incorporating a transplanted heart. At that time, I interviewed a 55-year-old transplant recipient who stated that when he was diagnosed with end-

stage heart disease the medical team offered him the opportunity to be listed for a heart transplant. However, he was unsure that organ transplantation was the right procedure for him. He explained that prior to this final diagnosis he had struggled with heart disease for a very long time and he had accepted the fact that he would soon die. Family, friends and the medical team, however, encouraged him to proceed with organ transplant. In the end, a heart became available for him and he progressed through the transplant process without any major difficulties.

For the first year and a half following his transplant he explained that he was unable to engage in any social activities, and during his hours of sitting in his rocking chair at the back of his house he thought about wanting to die. He was overcome by feelings of uncertainty and he stated he experienced severe symptoms of depression. His family members repeatedly told him that he made the right decision when he agreed to proceed with the heart transplant; otherwise, he would have died and no one was willing to accept that. At that moment during the interview his tone of voice dropped, his body slouched forward, he stared at his hands in front of him where he nervously played with a twist-tie and stated in a flat tone of voice, “now it’s ok, I’m fine now”.

During the analysis process, I was intrigued by the man’s comment that he initially accepted death to be inevitable, and how he made a different decision, which ultimately prolonged his life, based on statements from individuals around him. In the end, his statement “I’m fine now” in conjunction with his body comportment, demonstrated suffering and difficulties accepting how his life has been impacted by his decisions. During this research study, I became aware of the profound interconnectedness of physiological, psychological, social, and cultural facets of individual reality.

Knowledge gained during this interview sparked my interest in the interplay between social structure and individual agency in health and illness. Intrigued by the concept of the ‘social body’, I further investigated on how to best conceptualize and empirically engage with the less understood group of young adult transplant recipients. Of note, since my overall work is positioned within the field of health sciences, it was important for me to choose a theoretical stance that does not deny the ontological body. To that end, I started to review the work of Gilles Deleuze, Michel Foucault and Pierre Bourdieu more specifically.

Gilles Deleuze understands human life not in terms of the *being* of self-contained individuals but as the *becoming* of interconnected nodes of life. He understands that each of us forms one part of a chain of assemblages that never resolves into completed being but is always in process (Shildrick, 2009). For Deleuze conceiving the body as a mechanical assemblage implies that the body is multiple. Its function or meaning no longer depends on an interior truth or identity, but on the particular assemblages it forms with other bodies (Malis, 2004). Such a theoretical stance is compelling, since each of the transplant recipients will remain connected to others both materially and psychologically in terms of the incorporation of new body parts and the continuing biomedical interventions into their own bodies by drugs, mechanical links and possibly other prosthetic assemblages. To understand the body as hybrid, rather than singular and whole, may help recipients better negotiate the procedures that they will encounter. Then again, Deleuze’s conceptualization of the body is highly abstract and has rarely been incorporated into health science research, which made such an approach unfeasible for this research project.

For Michel Foucault the body and sexuality are cultural constructs, rather than natural phenomena. Judith Butler (1989) has presented a very powerful and influential critique of Foucault’s understanding of the body. Foucault argues, “bodies are constituted within the

specific nexus of culture or discourse/power regimes” (Butler, 1989, p. 602), and by doing so he has taken a stance that “there is no materiality or ontological independence of the body outside of any one of these specific regimes” (Butler, 1989, p. 602). Thus, his theoretical approach would lead to a research project similar to Deleuze’s, where one engages in an analysis of ‘bodies without organs’, which implies that the body is only accessible in the form of a discourse analysis. As a consequence, my theoretical literature review led me to the work of Pierre Bourdieu and his concepts of habitus and field. Habitus, as a concept, has potential to conceptually link psychological, social, cultural, as well as physical dimensions of young adult heart transplant recipients’ lives. Of note, and central to how habitus works as an explanatory tool, is the relationship between habitus, field and capital (Bourdieu, 1998). When engaging in empirical work it is therefore essential to think about how these concepts work in relation to each other, which will be explored in the following section of this chapter.

Pierre Bourdieu and his concept of habitus

The French Sociologist Pierre Bourdieu was influenced by two major intellectual currents during his formative years: existentialism and structuralism (Wolfreys, 2000). His thinking was shaped by the work of Sartre, one of France’s leading intellectuals at that time. Sartre, alternatively, was influenced by the German founder of existentialism Martin Heidegger and Edmund Husserl (Grenfell, 2008). Concomitantly, the works of French anthropologist Lévi-Strauss, as well French philosopher Merleau-Ponty were influential during this time. Finally, the works of Marx, Weber and Durkheim have also to some extent informed/shaped Bourdieu’s thinking and it is possible to see reflections of each of these scholars in his work (Grenfell, 2008).

Habitus represents one of Bourdieu's key concepts and provides a structure for thinking about and empirically analyzing the social world. It is his distinct contribution to the social sciences and a central concept in his philosophy of practice (Maton, 2008). A history of the questions that the concept strives to uncover would be a history of a wide variety of philosophical thought itself. Such questions are recurrent and have been addressed by other thinkers as well. A similar concept of "habit" appears in the work of Garfinkel (1967), Luckerman (1967), Schutz (1972), and James (1976). Concomitantly, Aristotle, Aquinas, Ockham, Merleau-Ponty, Elias, Husserl, as well as Weber and Durkheim have addressed comparable concepts to "habitus" prior to Bourdieu (Maton, 2008). Bourdieu highlights that the work by Hegel and his understanding of "ethos", Mauss's "hexis" and Husserl's "Habitualität" have strongly influenced his conception of habitus (Maton, 2008).

Habitus evolves from two central observations. First, individuals perceive themselves as free agents even though everyday decisions are made on predictable assumptions, various positions and feelings of others (Wolfreys, 2000). Second, social practices are rooted in consistent or predictable patterns (for example working class kids tend to take up jobs similar to their parents). There are however, no overt factors that justify this occurrence (Wolfreys, 2000). Habitus attempts to address such fundamental questions and Bourdieu states, "all of my thinking started from this point: how can behavior be regulated without being the product of obedience to rules?" (Bourdieu, 1994, p. 65). In other words, Bourdieu asks how the 'subjective social', and the 'objective self' shape each other and how social structure and individual agency become internalized and then reproduced in daily practices. Bourdieu elaborates that habitus is "a socialized subjectivity" and "the social embodied" (Bourdieu & Wacquant, 1992, p. 127, 128); to this end, it is the internalization of structures that renders the subjective, objective (Maton, 2008).

“The structures constitutive of a particular type of environment (e.g. the material conditions of existence characteristic of a class condition) produce habitus, systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles of the generation and structuring of practices” ... (Bourdieu, 1977, p. 72)...”practices produced by the habitus..., [are] always tending to reproduce the objective structures of which they are the product, they are determined by the past conditions which have produced the principle of their production...” (p. 71-72).

The concept of habitus concentrates on individuals’ ways of feeling, thinking, acting and being. It takes into consideration how we incorporate our history and how we bring our history into present situations, which leads us to act in very specific ways and not others (Maton, 2008). This is a very iterative process – we constantly are involved in creating history, shaped by circumstances not entirely of our own making. Time and again, we make decisions or take actions based on various beliefs or events that have shaped our course (Maton, 2008). We make decisions based on the range of options available to us at that moment, the possible choices visible to us, our disposition (habitus), and the embodied experiences of our journey (Maton, 2008). On the other hand, our choices will also shape our future possibilities. To make a choice also means to forsake alternative options, this will then shape our new path and our understanding of the world and us in general (Maton, 2008). To this end, the social practices produced by the habitus are not static, but represent a fluid process – they are robust and exchangeable but not absolute.

Concomitantly, habitus also implies a practical understanding of what needs to be done in a particular situation. Bourdieu (1998) introduces the notion of having a “feel-for-the-game”, which refers to the art of anticipating what is going to happen next in a given setting or social situation. For example, Bourdieu uses the analogy of a tennis player; a good tennis player does not stand where the ball is, but moves in the direction where the ball is going to be. The player is

anticipating where the ball is going to be next and his actions are embedded in the game. He has the tendencies of the game incorporated in his body; he embodies the game (Bourdieu, 1998).

...such position is without doubt the feel for the game: the player, having deeply internalized the regularities of a game, does what he must do at that moment it is necessary, without needing to ask explicitly what is to be done. He does not need to know consciously what he does in order to do it even less to raise explicitly the question of knowing explicitly what others might do in return (Bourdieu, 1998, p. 98)

For Bourdieu (1998) the habitus is a socialized body that has incorporated structures of a particular social environment that then further shape an individual's view of the world as well as actions in that setting.

Every reality with all its established structures tends to reproduce social orders, which are in most cases taken for fact (Bourdieu, 1977). Bourdieu (1977) commented that these realities, with all its arbitrariness, are accepted without reflection on the nature of reality or that things might not have to be that way. Individuals take certain actions that reproduce particular classifications that they are a product of that particular social environment. As such, individuals engage in a (mis)recognition by uncritically affirming that which they are a product of (Bourdieu, 1977).

Schemes of thought and perception can produce the objectivity that they do produce only by producing misrecognition of the limits of the cognition that they make possible, thereby founding immediate adherence ... to the world of tradition experienced as a "natural world" and taken for granted (Bourdieu, 1977, p. 164).

Individuals are a product of and reproduce particular structures that lead to immediate complicity, these systems are seen as self-evident and undisputable and as such encounter no rival or opposing principles (Bourdieu, 1977).

Field

Habitus does not work alone and needs to be explored within social space. Bourdieu is not suggesting we are pre-programmed, only acting out the implications of our socialization and acclimatization to social contexts. In order to better understand individuals' behaviour within a particular social situation, it is not sufficient to only examine behaviour or speech; it is essential to also reflect on the social space in which a specific phenomenon occurs (Bourdieu 2005). In addition, when analyzing social space it is not adequate to locate an individual within a particular historical, relational, local and international context, but also to examine how knowledge about a particular individual or group came into place, who was involved and who benefited from this practice (Bourdieu, 1994). Social space, or field, as Bourdieu named it, is a setting in which individuals and their social positions are located (Bourdieu, 1998).

Bourdieu's concept of a social field is frequently compared to the analogy of a football field, composed of social agents (individuals or institutions) who occupy particular positions within a field. What happens on or in a particular field is ultimately bordered and restricted (Thomson, 2008). There are rules that constitute the logic of that particular field and these rules are incorporated within the bodies and practices of the players (Thomson, 2008). In parallel, barriers are constructed that impact what happens inside the football field and what goes on outside. These erected barriers, which could be compared to the glass ceiling in the business world, keep individuals safe within a small self-contained world and activities inside these social worlds underlay regular patterns that demonstrate some predictability (Thomson, 2008). Within these fields, social order is hierarchically structured in order to maintain function, which means not all players are equal and that fields are sites of social struggle (Thomson, 2008). Hence, there are some people that hold more power, which enables them greater input into the functional

logics of the social world (Thomson, 2008). Bourdieu (2005) highlights that rules in a particular self-contained social world are similar to other social spaces. Even though there are always variations, there is a common pattern of operations among social worlds and these small social worlds are comparable to larger social spaces (Bourdieu, 2005).

Bourdieu (2005) suggests that fields are composed of opposing forces as observed in a force field in physics. He argues that cultural and economic capitals operate as two hierarchical opposing forces in a field. The field can be understood more like a magnet and positions are determined by their relationship to the two poles. Having more economic capital within a field always brings more status and power than cultural capital, although, having a combination of both is always more profitable in the field of power (Bourdieu, 2005). In a physical force field, however, there are no precise boundaries and its force exists only as far as its effects (Bourdieu, 2005). To this end, in a physical force field struggle is about boundaries, its borders and the values of various capitals (Bourdieu, 2005).

In this study, the health care system was conceptualized as one such particular field. More specifically, the Sick Kids Hospital and the University Health Network were approached as two self-contained fields. Within these social worlds, young adult transplant recipients, health care professionals, friends and families are social agents who occupy particular positions. Government and hospital rules and regulations are in place that provides logic for who can be served within these fields. In keeping with Bourdieu, these rules are incorporated within the bodies of the individuals. Health care professionals, for example, communicate and interact with transplant recipients in very specific ways. Transplant recipients, alternatively, stand, speak and interact with health care professionals in a certain manner and consequently comply with rules that are particular to the health care setting. Since health care professionals, transplant recipients,

family and friends do not all occupy equal positions within the field, there are social hierarchies that shape the rules of the field. Thus, individuals within the field contribute to the construction of barriers of their social world and by doing so shape their particular field.

Bourdieu (1998) highlights the fact that a submission to an established order within a particular field has frequently been imposed through struggles of dominant and dominated groups. The result of such struggles is frequently a particular misrecognition of this arbitrariness, which is taken up and recognized as a fact. Bourdieu (1998) calls this experience *doxa*, where the order of the social world is seen as natural and self-evident and as such neutralize their specific arbitrary character. This mode of *doxa* means that individuals recognize an immediate connectedness and ease being in a particular field, and as such experience the field as natural, being shaped by the traditional world. The field of *doxa* and its implied self-evidence is greater the more stable objective structures are in a particular social formation and the more successfully they are reproduced in the dispositions and actions of individuals. To better comprehend dispositions of agents in a field it is not sufficient to understand the underlying structures, but also individuals who had particular interests and took actions during times of struggles. In order to better understand a field, therefore, it is essential to reflect on the players who hold certain positions and shape a given field.

Capital

At stake in a field is the accumulation of capitals: they are both the process within, and product of a field (Gibson et al., 2007). Generally, the term “capital” is associated with financial and economic interactions. Bourdieu (2006), however, conceptualized capital to include wider systems of exchanges, whereby assets of different kinds are transformed and exchanged within

and across a variety of social networks or fields. He moves away from a narrow understanding of economic and financial exchanges into a wider conceptualization that includes various forms of cultural exchanges (Bourdieu, 2006). Cultural exchanges are captured in the form of symbolic capital which are further divided into sub-types such as social capital, cultural capital, scientific capital et cetera, depending on the field in which they are located (Moore, 2008). To this end, economic (though the most important) capital is not the only type and social, cultural or scientific capital can be thought of as essentially transformed types of economic capital (Moore, 2008).

An outline of some of Bourdieu's most prominent forms of capital are provided in the following paragraph, however, no claim is being made that all were salient for this research. Bourdieu defined economic capital as a "private possession of the means of production" (Bourdieu, 1998, p. 16), which is any form of material wealth, including possession of time or the capacity to organize the time of others around one's convenience (Bourdieu, 1998). Cultural capital can be observed in an embodied state, for example, "in the form of long-lasting dispositions of the mind and body" (Bourdieu, 1986, p. 243); in an objective form, which can be observed in the form of cultural artefacts; and in an institutional state, which is seen in the form of educational qualifications (Bourdieu, 1986). Social capitals are formal and informal networks, like mutual acquaintances or institutional relationships, or memberships to a particular group (Bourdieu, 1986). It was expected that some of these presented symbolic capitals will be observed in the study, which required an in-depth analysis of cultural exchanges with various fields.

As Bourdieu broadened his conceptualization of capital, he addressed a primary distinction between economic capital and symbolic capital that is critical to understanding how

these concepts operate. Within Bourdieu's system, economic exchange carries with it a certain aspect of transparent self-interest that always represents a means to an end (profit, wage etc.) (Moore, 2008). The understanding here is that economic exchange does not entail any intrinsic worth, which has been argued exists when artists 'create art for art sake'. Bourdieu argues that this also holds true in various forms of symbolic capital; however, here, individuals proclaim a disinterest in various gains and argue for an intrinsic worth (Bourdieu, 1977). For example, in the scientific world, knowledge is pursued by the researchers' interest for the truth, denying any self-interest. Bourdieu argues that such forms of altruism represent a systematic denial of the fact that symbolic capitals are altered forms of economic capital (Bourdieu, 1977). Such misrecognition establishes forms of hierarchy and discrimination by arguing that certain undertakings are more worthwhile than others (Bourdieu, 1977). To this end, Bourdieu argues that a gain in symbolic capital is essentially also based on interest.

Bourdieu's conceptualization of capital and how it is applied throughout his work creates a concept with very distinct characteristics. There are two important features when engaging with forms of symbolic capital. First, values, tasks and a specific lifestyle of some social groups elevate these groups over others that grant them social advantage (Bourdieu, 1998). This can be observed when forms of habitus are held in common among individuals in different social groups by virtue of power relations in society and by defining commonalities and differences (Bourdieu, 1998). Belonging to a specific social class, however, does not automatically translate into a habitus that awards symbolic capital to all its members. Second, forms of capital such as cultural capital can be understood as different forms of awareness and realization within social groups; which for example, represents divisions among classes rather than classes in themselves (Bourdieu, 1998). Thus, differential distribution of capital within one class may hinge on

intersecting group memberships, for example, gender, age ethnicity, et cetera. Here, habitus represents a mastery of some technique(s) or cultivation of one's consciousness (Bourdieu, 1998).

The outlined distinction is essential to understanding Bourdieu's conceptualization of symbolic capital. All areas of social practice will include various nuances of what Moore (2008, p.103) calls a "well-formed habitus". Symbolic forms of capital are associated with a "well-formed habitus" and individuals within various groups who have a higher level of a "well-formed habitus" confer higher cultural capital (Moore, 2008, p.103). The significance here is that the concept of symbolic capital facilitates new avenues of analysis by investigating variances and effects within particular groups because it illuminates divisions within groups rather than simply differences among groups (Moore, 2008).

The effects of symbolic capital and its "well-formed habitus" are constituted and sustained by what is essentially claimed to be the intrinsic principle of a particular field. To this end, fields are means of producing different types of symbolic capital and the rules of social distribution of those capitals (Bourdieu, 2006). "Capital can be understood as the 'energy' that drives the development of a field through time. Capital in action is the enactment of the principle of the field. It is the realization in specific forms of power in general" (Moore, 2008, p. 105). In order to demonstrate how this is accomplished, Bourdieu (2006) highlights that various types of capital can exist through different forms. Capital can be objectified in forms of artefacts of different kinds, for example, art works, books, museums, concerts (Bourdieu, 2006). Concomitantly, Bourdieu highlights the formation of capital in the form of habitus. Since habitus represents one's disposition it is not to be found in any form of material existence like objectified capital. That is, rules are not found in any material existence, but are taken up and realized in

practice (Bourdieu, 2006). To this end, habitus is initially formed within the family, but for Bourdieu, various forms of education assume essential roles in creating capital in the form of habitus.

“Most of the properties of cultural capital can be deduced from the fact that, in its fundamental state, it is linked to the body and presupposes embodiment. The accumulation of cultural capital in the embodied state, i.e. in the form of what is called culture, cultivation, Bildung, presupposes a process of embodiment, incorporation, which insofar as it implies a labor of inculcation and assimilation, costs time, time which must be invested personally by the investor” (Bourdieu, 2006, p. 107).

Habitus and Hexis

Bourdieu calls the embodiment of habitus hexis (Bourdieu, 2006). For Bourdieu, a bodily hexis is essentially a physicality that links with social positioning, which is realized and embodied through various types of predispositions and consciousness (Bourdieu, 2006). This signification is visible through physical features such as body comportment, language, feeling and thinking (Bourdieu, 2006). Therefore, for Bourdieu, then, social and cultural dispositions are embedded and mapped on the body. The body incorporates history and reproduces history in ways that are primarily unconscious to the individual. Thus, fundamental values and dispositions of individual groups are embodied in the individual rendering it visible for further inspection. Capital is objectified as habitus and is embodied and realized in practice (Moore, 2008).

In sum, symbolic capital is a type of asset that might lead to cultural and social advantages or disadvantages (Bourdieu, 1998). Through Bourdieu's argument that symbolic capitals are altered forms of economic capital, the field of symbolic capital is a structure that has the same evolutionary origin as the structure of the economic field, but with its own unique function (Bourdieu, 1977). Each field of symbolic capital, with its groups of individuals and its underlying relations of power, creates and reproduces a system of inequality as signified within

the economic field (Bourdieu, 1993b). Symbolic capitals are institutionally distinct and distanced from economic capitals, composed of their own ideology and reasons, in the end however, they are 'reversed' economic fields (Bourdieu 1993b).

Current uses of habitus, field and capital in health sciences

Bourdieu's understanding of practice provides a theoretical underpinning on how to conduct research in the health sciences. Bourdieu's work attempts to expose the relationship and interconnections among individuals and structures within a social field. Epidemiologists and researchers in the health science field have long studied these relationships, which were brought to the foreground by Bourdieu, as they attempt to make links between disease and social circumstances (Frohlich et al. 2001). More recently, work by Gibson et al. (2007) has drawn on Bourdieu's theory to explore the identities and social positioning of men with Duchenne muscular dystrophy. The team highlighted that study participants have been marginalized through the inaccessibility of their built environment, various arrangements that make it difficult for them to socialize, and reactions of other people based on their visible difference. But more importantly, study participants' marginalization was embodied, which was observed in individuals' deep sense of resignation, by accepting marginalization as 'normal', but troubling.

A study conducted in Finland focused on fields and examined absenteeism during sickness, whereby a multitude of health-related behaviour and socio economic positioning was explored, which provided insight to the overall field (Virtanen et al. 2000). More specifically, the team explored how the relationship of the everyday, with being ill, and absence from work due to illness is being discussed using the concepts of habitus, capital and practice by Bourdieu. The team concluded that sickness absence is an expression of a specific habitus, which is deeply

rooted in the social history of the local community. Work conducted by Morgan et al. (2009) examined the impact of social capital on adolescents' health. The study was based on the recognition that social capital impacts health related behaviours, which are shaped by an individuals social networks and relation with ones community. Additionally, Bourdieu's theories have been successfully incorporated in analyzing the complex field of welfare (Peillon, 1998). Since studies of entire fields are very complex and not always feasible a recent Finish study incorporated only specific aspects of Bourdieu's theory to explore older individuals' use of medication. The study is valuable by highlighting how older people view themselves within a particular field (Lumme-Sandt & Virtanen, 2002).

Critical analysis of potential limitations of Bourdieu's concepts

As demonstrated above, the work of Bourdieu is useful in developing research projects in the health sciences. Nevertheless, there are potential concerns that have been addressed by scholars when adapting Bourdieu's view of social life into research. Critique is provided based on the capacity of how habitus works as an explanatory tool by focusing on the relational structure between habitus and field. In Bourdieu's conceptualizations of habitus and field, neither are objectively determined nor products of free will (Bourdieu, 2008). Habitus concentrates on individuals' ways of feeling, thinking, acting and being, which subsists in individuals' bodies and minds. Fields are conceptualized as a set of relations in the world. In Bourdieu's concept of practice, fields have an impact on one's habitus and habitus shapes fields (Bourdieu, 2008). Practice is formed between the interconnection of 'inside' and 'outside' and its structures are not directly observable. To this end, agency is only observable in the form of subjective experience

and scholars have argued that Bourdieu's theory preserves an objectivist bias from structuralism (Bourdieu, 2008).

Additionally, within analysis based on the concept of field, one emergent concern becomes the question of borders, as it is often difficult to determine where the effects of any given field end and another begins. Fields can often seem to be fuzzy and potentially can be contested (Thomson, 2008). Researchers might also struggle with the problem of too many fields. One of the more consistent critiques of Bourdieu's work is that it is too focused on already determined aspects of field and habitus, or at the very least his concepts dwell too much on reproductive aspects and not their changeability (Thomson, 2008). In Bourdieu's reference to habitus it appears that an individual's social habitus is already predetermined and there seems to be very little room for change in one's individuality (Thomson, 2008). Nevertheless, Bourdieu describes his concepts of habitus and field as being sites of struggle and this implicitly leaves room for changeability.

Chapter Summary

Bourdieu's concept of habitus offers a useful structure to think about young adult transplant recipients within their social world. His concepts provide a theoretical underpinning on how to empirically engage with the phenomenon. Central to how Bourdieu's (1998) conceptualization of practice works as an explanatory tool, is the relationship between habitus, field and capital. The concept of habitus refers primarily to the characteristics of an individual, with its theoretical understanding that habitus is acquired through an ongoing social process. Fields are fairly independent structures such as the healthcare system, the education system or families that have their own rules of understanding (Gibson et al., 2007). Fields are composed by

the juxtaposition of social positions, that is, the mutual exclusion or distinction of persons or groups from each other (Gibson et al., 2007). Fields are competitive, with various social agents, using differing strategies to maintain or improve their position. At stake in the field is the accumulation of capitals: they are simultaneously active within, and the products of, a field. Capital is any resource that is acknowledged as useful within a given field (Gibson et al. 2007). Crucial for understanding Bourdieu's approach is the interlocking nature of habitus, field and capital. He argues for a methodology that combines these three concepts as an interdependent and co-constructed view of the social world, with none of the concepts being viewed as having primary dominance. His work is based on relationships and interconnectedness of individuals and structures within a field, with the potential to plot new and interesting directions for research in health sciences.

CHAPTER 4: METHODOLOGY

Introduction

This doctoral research study explored how young adults resituate themselves within the logics of a new field of health service consumption; how they re-inhabit their bodily practices of self-care; and how they are inculcated with new forms of capital as patients in an adult health care facility using an innovative visual interview technique. As the main researcher, I first highlight personal assumptions about knowledge production in general and, more specifically, Bourdieu's approach to social research. As a graduate student, I have been intrigued by researchers' work that is based on the understanding that human interpretations are the starting point to develop knowledge about the social world (Prasad, 2005). "What is paramount is how we order, classify, structure, and interpret our world, and then act upon these interpretations" (Prasad, 2005, p. 13). Following Bourdieu, I espouse a realist inquiry but acknowledge a relativist epistemology. In other words, there are potentially multiple and situated interpretations of reality, but a phenomenon exists independent of these perspectives. Central to Bourdieu's approach is the way in which the research object is constructed by health sciences researchers (Grenfell, 2008). He encourages researchers to approach a specific phenomenon in an unexpected manner by making the everyday strange and to think relationally about habitus, field and capital in a research project (Bourdieu, 1977). To this end, Bourdieu (1977) highlights the importance of breaking away from the pre-constructed object as it has been studied within a particular field. Thus, thinking relationally in this research project means engaging with organ transplant recipients, their relation to other people and organizations at a specific time and place.

The Goals Of The Study Were:

1. To explore how young adult transplant recipients resituate themselves within the logics of a new field of health service consumption;
2. How they re-inhabit their bodily practices of self-care; and
3. How they are inculcated with new forms of capital as patients in an adult healthcare facility.

Research Design

Using qualitative visual methods I conducted an exploratory study of young adults who have received a heart transplant in childhood and have recently transitioned from a paediatric setting to an adult healthcare facility. Drawing from the work of Pierre Bourdieu (1984) and visual methodologists Sarah Pink (2007) and Christian Heath (1997, 2002, 2010), I audio/video recorded twelve study participants and analyzed spoken words and body gestures. My methodology involved an iterative, three part process to capture the salient features of individuals' social interactions in everyday life to address the research objective.

Recruitment

Participants were identified via OTTR (outpatient transplant tracking record). During a routine clinic visit, each potential participant was approached by the heart transplant coordinator (who is independent from the study) and provided with a recruitment package (see appendix - A) including a letter from the clinic director, summary of the project, my contact information, copy of the approved consent form and a response form. I approached participants who were potentially interested in the study and reviewed with them the research materials in detail,

answered questions about the study and explained the interview process. Potential study participants were not asked to enrol in the study until the following routine clinic visit. It was anticipated that the delay between reviewing the package and approach for informed consent allowed potential participants time to reflect and to contact members of his/her healthcare team for further information. This opportunity for reflection and contact was central to enhance participants' feelings of control (Brown, 2006) and also ethically important to avoid coercion. During the second clinic visit, I contacted the participant again, and once informed consent was obtained an interview was booked at the participant's convenience. Additionally, information was gathered on reasons for refusal.

Data collection

The study was designed according to the tenets of visual methodologists Pink (2007) and Heath (1997, 2002, 2010). Visual methods have had a place in ethnography since the 1920's (Bunzel, 1990), including the use of 'photobiography' and digital film/video observation and analysis. It is a distinct body of sociological research concerned with the ways in which talk and bodily conduct feature in social interaction (Pink, 2007). Conventional methods, both qualitative and quantitative, fail to yield adequate information about important issues of embodiment and identity. Also, textually based methods do not reveal the subtleties of physical communication of habitus, for example, the gestures, postures, manners of the body as the participant speaks.

After informed consent was obtained, over the course of seven months, visual observations and interviews were conducted with young adults who had a heart transplant in childhood. I conducted a single interview with each participant for the following reasons: a) theoretical: findings do not claim to be truth-based but represent the 'self' as a fluid and

accessible only at given moments in time, b) feasibility: the number of interviews was limited to twelve due to anticipated volume of data. The viability of this approach has been substantiated by interviews that have been conducted as part of a prior research study at the University Health Network that focused on how adult transplant recipients incorporate a transplanted heart (Ross et al., 2010). The study required 19 months to complete with 7 months for data gathering, started in May 2012, and 12 months for data analysis and report writing. The timeline is shown in Appendix D.

Sample Size

Consistent with theoretical assumptions about qualitative visual methods video materials are very rich data sources and even small numbers of study participants can deliver copious data (Heath, 2010). Sample size was based on a similar study conducted by Gibson et al. (2007); however, recruitment continued until no additional data were obtained. The study consisted of 12 young adult transplant recipients who have recently transitioned from Sick Kids Hospital to the outpatient transplant program at the University Health Network.

Inclusion Criteria

Participants had to be between 18 – 29 years of age, had received a heart transplant in childhood, and recent transitioned from a paediatric to an adult healthcare facility.

Exclusion Criteria

Heart recipients who were unable to give informed consent, had psychopathology identified pre or post transplant, and were not fluent in English, were not recruited for this study.

Data recording

Each individual was interviewed for approximately one hour. I aimed to elicit participant accounts, including their bodily mannerisms to reveal how young adults resituate themselves within a new field of health service consumption and how they re-inhabit their bodily practices of self-care.

The overall interview approach was guided by Bourdieu's (1999) methodological and theoretical focus on life circumstances, activities/practices and the logics that coordinate them. In order to engage study participants in true conversations, Bourdieu (1999) asks interviewers to be aware of the way we look at other people in ordinary circumstances of their lives. The understanding here was that I reflexively consider the effects I might have had on the interviewee. This implied that when I interviewed study participants, I had an understanding of what could be said and what should be avoided in order to foster non-violent communication. For Bourdieu (1999) non-violent communication means avoidance of symbolic violence, which refers to imposing one's own view on the participants' reality. What was required was the creation of a relationship between myself and the interviewee based on an active and methodical listening that was achieved by adopting the study participants' way of communicating and adhering to their personal positions and view of the world (interview guide Appendix B).

In his book 'The weight of the world', Bourdieu (1999) and his collaborators showcase dozens of interviews with people living in hardship in one form or another, at the extreme margins of society. Bourdieu's interview style was more representative of a dialogue with questions focusing on: who..., when... and where... in order to better understand participants life circumstances. Hence, I used prompts such as "Who helped you with this and how?", "When

did this occur”, “Where did you experience this?”, “What else was going on in your life at that time?”

All sessions took place in a private quiet room removed from the clinic area in the hospital. All interview sessions were one-on-one. Following Usher and Holmes (1997), about 30 minutes were spent at the start, establishing rapport and trust with the participant as well as answering any final questions about the research. A brief orientation to the equipment was given along with instructions on how to turn the camcorder off at any point during the session should the participant so desire.

I began the formal session using a standardized introduction (see Appendix - C). In keeping with conventions of semi-structured qualitative interviewing, prompts/questions were utilized when necessary, as were techniques such as nodding, tolerating silence, and using phrases such as “would you feel comfortable telling me more about that?” This is also consistent with process consent, which means that I did not take informed consent as full discretion to invade all areas of the participants’ life. I constantly checked in with the participant to make sure they are willing to discuss a topic. Given that the study was informed by the work of Pierre Bourdieu, more specifically his conceptualization on how capital is visible in the form of objectification, embodiment and formation of habitus, this study did not privilege speech as the route to explore the participants lived experience. Therefore, during the interview sessions, I also attended to participants’ physical comportment, body language, use of personal artefacts (i.e. jewellery, religious icons), and mannerisms such as sitting position, hand gestures, arm movements, facial expressions, as well as tone of voice, pace of speech, coughs, laughter and pauses. In keeping with Bourdieu (1984), he alerts us to the use of language and terminologies, the modes of dress and gestures that signal age appropriate behavior, or otherwise, and sings of

ongoing social struggle or conflict, for example, agitation when discussing some topics, as opposed to a relaxed posture. Thus, audio/video observational techniques were used because they are methods that are congruent with Bourdieu's understanding on how capital is formed and manifested. These techniques included the use of an unobtrusive digital streaming audio/video camera to record the interview.

Much has been said about the methodological value of using a video camera to collect data (Albrecht, 1985; Erikson & Schultz 1982; Gottdeiner, 1979; Grimshaw, 1982; Heath, 1986) with various cautions around 'contamination' if participants know they are being filmed. Given my theoretical orientation in this research study, however, I believed one cannot observe the world without being present in it and involved in its constitution. Thus, I accepted that the use of video, far from being a means of neutrally reproducing social activity, is itself a fundamental part of new knowledge production. Indeed, the camera, as Pink (2007) argues, becomes an actor in the process. It remains purposely visible, static and positioned to capture both interviewer and participant 'in the frame'. Considered an 'actor' in the session, the camera was made visible to the participant. As soon as possible after each session, compiled detailed field notes and observations. After each session, all digital audio/video files were immediately transferred to a password protected, project specific, secure research server.

It was anticipated that during the interview participants could become fatigued, distressed or unable to continue. Great care was taken to ensure that participants knew they could take breaks as needed, or postpone to a later date. I respected the right of the participant not to continue with the study if s/he desired. None of the participants elected to take a break or stop the interview process altogether. I approached the interview process with an empathic demeanour and offered/provided support to the participant during the time of the study. I

anticipated that these measures would create trust and openness between the researcher and the participant.

At the end of the session, I was available to provide support to the participant. In addition, standard UHN practice provided all transplant patients with access to 'easy-call'. This confidential system was available for all clinical concerns patients experienced post transplant. The transplant coordinator responded to these messages within the day. After hours and on weekends, urgent issues were routed to the transplant floor where there was access to an on-call transplant coordinator, heart transplant fellow and heart transplant staff. Questions could also be referred to other appropriate support professionals. I anticipated that these measures would create trust and openness between myself and study participants.

Data Management

For the purpose of this study, all conducted interviews were transcribed verbatim by a transcriptionist trained in using coding conventions established by Poland (1998, 2001). This technique allowed for coding of pauses, silences, awkward moments, and laughter, in addition to dialogue. Transcripts, field notes and digital video files were imported into NVivo 9 research software program. NVivo 9 was best suited to the study because it allowed for storage, organization and analysis of demographic, visual and verbal data, as well as simultaneously viewing and analyzing.

All abstracted demographic data, as well as audio/video recordings and transcripts were stored on the UHN password protected, project specific, secure research server. The hard copy was retained within a locked filing cabinet within a locked office. After each session, all digital audio/video files were immediately transferred to the UHN password protected, project specific,

secure research server. Project files were kept in a locked office. Data, including audio/video footage, were only made available to the PhD committee members, via the secure UHN password protected, project specific, secure research server.

Data Analysis

Data analysis was shaped by Bourdieu's (1977) theory of practice and how habitus and its interconnection with field and capital provide a framework for conceptualizing the social world of transplant recipients. The understanding here was that research participants offered their accounts of the social world, beginning from where they perceive the phenomenon at different times and places. In keeping with Bourdieu's work, I engaged in three distinct levels of analysis (Wacquant, 1992). First, it was necessary to look at a particular field and how it connected with other fields, particularly with the well-recognized field of power (Wacquant, 1992). Second, the structures of a particular field needed to be observed, which included a detailed analysis of all individuals from the perspective of the study participants, within a particular field and the various positions that they hold (Wacquant, 1992). To this end, positioning within a field was expressed in terms of various different kinds of capital (Wacquant, 1992). Capital was the recognized form of exchange within a field and based on scarcity that defines individuals' positions within a field. Third, individuals' characteristics within a particular field were analyzed as they related to their past and present (Wacquant, 1992). Relations and complexity of individuals' position within a field and its subsequent forms of capital were determined by the various principles and priorities of a particular field. Thus, one's position within a particular field was directed by one's habitus in terms of arrangements of capital and how this resonated with the structuring rules within a particular field (Wacquant, 1992).

Bourdieu's approach to analyzing research data was used to provide a theoretical lens; his insights were used to enhance my analysis of the interplay between the subjective social and the objective self (Wacquant, 1992). To that end, interview content was reviewed for participants' life circumstances, and videos provided information about the body and embodiment of capital. The structures of data analysis, however, were theoretically driven by techniques described by visual methodologist Pink (2007) and Heath (1997, 2006, 2010).

Several texts have been published on visual methods over the last few years. The most useful are the work by Pink (2001) *Doing Visual Ethnography*, Van Leeuwen and Jewitt's (2001) edited *Handbook of Visual Analysis*, and Banks's (2001) *Visual Methods in Social Research* (Harper, 2005). The work of Pink (2001) has been included in this research since she studied visual methods broadly. Heath's (2010) approach added additional insight, since his work was based on his own research that has been conducted over the last few decades, which included video-based research on organizational environments, including consultation practices of physicians and operating rooms in hospitals. All of Heath's research was primarily qualitative, drawing on ethnomethodology and conversation analysis (Heath, 2010).

In visual methodology the assumption is that images and words contextualize each other, forming a set of different representations "evocative of emotions and experiences" (Pink, 2007). In practice, this implied an analytical process of making meaningful links between different experiences, visual data and other objects. These different media represented different types of knowledge that may be understood in relation to one another (Pink, 2007). Images and word contextualized each other, forming a set of different representations and strands of the phenomenon.

Visual methodologist Sarah Pink (2007) commented on the use of still photography and video in qualitative research and argued that the researcher must remain highly reflexive on how one experienced the exiting new knowledge of image and words. She argued, “video materials should be treated as representations rather than visual facts and their analysis should take note of the collaborations and strategies of self-representation that were part of their making” (p. 88). Concomitantly, Christian Heath (2006) used video cameras to capture “*expressive gestures*” and how they are used in talk to reveal the “*emotional and personal experiences*” (p. 597) of patients when visiting their doctors. Heath’s (2006) “paper examines how gesture and other forms of bodily conduct were used to transform symptoms into suffering: to display, enact and (re)embody medical problems and difficulties” (p. 579). To this end, Heath (2006) used large sample sizes and worked with study participants at various times during the research study.

Heath (2006) analyzed video-recordings over a period of many years and concluded that during interviews participants sometimes point to visible manifestations of their condition such as a rash or scar, but mostly there is no visible proof of suffering. “The patient has to provide the sense and significance of the illness and its symptoms through talk and bodily conduct” (p. 599). Heath finds that descriptions of experience are accompanied by gestures that locate “the areas of difficulty and give a flavor of particular symptoms” (p. 600). Observing a woman trying to communicate with her doctor, he wrote, “her subjective experience of the symptoms is overlaid, played out across the relevant parts and surface areas of the body” (p. 601), and “the doctor momentarily becomes a spectator, witness to the symptoms that the patient has experienced” (p. 603). Thus, Heath (2006) finds the body becomes a tool in communicating suffering, for “enactment and demonstrations display the unique and particular qualities of pain and suffering- they give a distinctive sense and significance to generic categories of complaint and symptom

and they provide particular characteristics to conventional ways of describing and diagnosing illness” (p. 613).

Notably, Heath (2006) finds “the more dramatic demonstrations” arise “in circumstances where there is a potential tension, or *incongruity*, between the patient’s assessment of the complaint and the doctor’s diagnosis. ***“Through gesture, bodily comportment and talk, they render visible what would otherwise remain hidden and unavailable for inspection”*** (Heath, 2006, p. 615). Thus, data analysis was based on the premise that images and words contextualized each other and were “evocative of emotions and experiences” (Heath, 2006, p. 30). Analysis included transcripts and participant’s physical comportment, use of personal artifacts (i.e. jewelry) and mannerisms (Heath, 2006). The video and transcripts were analyzed simultaneously and in an iterative process.

The analysis was iterative, continued in three steps, which included critically exploring the relationship between visual and verbal data (Pink, 2007). There were several reflexive reviews of the videos, by myself and with my academic supervisor in order to discuss the directions for analysis. In the first phase, I conducted a preliminary review of the data and time-logged the digital file, making notes of any ‘key moments’ where verbal or bodily ‘statements’ might be explored. I used logging and transcription to map visual and verbal knowledge otherwise only accessible linearly, to make findings more easily available (Pink, 2007). The goal here was to capture simple descriptions and classifications of young adults’ accounts of their transitions from paediatric to adult health care for the first set of broad themes (free nodes).

In the second phase, I collapsed these broad themes into descriptive codes (tree nodes). Following this process, a more substantive review of the data was performed. Throughout, and following Heath’s work, I watched for any “expressive artefacts” such as an open necked shirt to

show the surgical scar, “expressive gestures” (Heath, 2006, p. 32) that could locate “areas of difficulty” on/in the body (i.e. hands on heart, pointing, rubbing) (Heath, 2006, p. 32), and “by the way syndrome”, i.e. the gestures and comments close to the end of the interview that may “(re)assert the significance or seriousness of a particular symptom/feeling” (Heath, 2006, p. 32). “Incongruities” or disjuncts between the recipients’ words and gestures – either the upgrade of speaking positively even when body comportment indicated distress or the downgrade when body comportment showed no distress, yet words told another story – were noted (Heath, 2006, p. 32). In keeping with Bourdieu (1980), he also alerts one to the use of language and terminologies, the modes of dress and gestures that signal age appropriate behavior, or otherwise, and signs of ongoing social struggle or conflict, for example, agitation when discussing some topics, as opposed to a relaxed posture.

Finally, all descriptive codes were discussed, debated and reviewed with members of the PhD committee before being collapsed into analytical categories that took up issues around how young adults outer social and inner self reconstitute each other. Working with the generated analytic categories, video footage and stills and a report was generated to address the study’s research objective. Following Heath (1997, 2006), the report included excerpts of transcribed text and approved images from the digital media files.

Methodological Rigor

To meet the highest standards of methodological rigor, an audit trail was maintained (specific record of methodological and data coding decisions). Transcripts were typed verbatim by an experienced transcriptionist and reviewed by myself for accuracy. The flexible storage, cross-indexing, and quick retrieval features of *NVivo 9* made it easy to search for negative

instances and universal findings (Conrad, 1984). Attention was paid to ‘surprises’ inconsistent with overall findings, and coding was discussed with members of the PhD committee. Issues not resolved through consensus lead to discussion and further analysis.

Criteria for Judging Research Quality

Given the assumptions underlying this realist inquiry that acknowledges a relativist epistemology, it was not possible, nor desirable to assess the quality of this health proposal with a set of analytic criteria from a positivist tradition (Guba & Lincoln, 2005). Guba and Lincoln (2005) established hallmarks for authenticity, trustworthy, rigorous, qualitative inquiry. The health inquiry drew on four sets of those hallmark criteria in order to judge process and outcome of the health inquiry: a) fairness, b) catalytic and tactical authenticity, c) reflexivity (Guba & Lincoln, 2005). These criteria are addressed in detail in the conclusion section of this dissertation.

Ethical considerations

The study was approved by the UHN Research Ethics Board (see appendix – B).

Risks

It was anticipated that participants may become fatigued, distressed or unable to continue during the interviews. Great care was taken to ensure that participants know they may take breaks as needed, or postpone to a later date. I respected the right of the participant not to continue with the study if s/he desired. None of the study participants elected to take a break

during the interview or stop it all together. I offered/provided support to the participant, and arranged for further assistance as needed.

Benefits

There may be no direct benefits to participants, although some benefit from being encouraged to reflect upon and discuss their experiences. The findings provide a more critical and nuanced understanding that fills a major gap in current knowledge. New approaches or interventions based on these findings will help us better prepare potential recipients, support them post transplant and improve their well-being.

Additionally, the consent process included a detailed section/discussion on the use of video images (Charmaz, 2002; Poland, 2001) (see appendix A). Three options were presented to participants. Option 1: video footage/images will only be viewed by the participant (if s/he wishes), interviewer and PhD committee members for purposes of data collection and analysis. No images of the participant will be used in any knowledge translation/reporting activities. Option 2: Video footage/images will be viewed by the participant, interviewer and PhD committee members for purposes of data collection and analysis. No unique *identifying* images will be used. Option 3: Video footage/images will be viewed by the participant, interviewer and PhD committee members for purposes of data collection and analysis. The participant also gave consent for potentially identifying images to be used in knowledge translation/reporting activities (i.e. footage may include images of the face).

CHAPTER 5: RESULTS

PART ONE: YOUTH, IN THE HEART OF AN ADULT WORLD

Introduction

The results of the study represent a Bourdieusian analysis of transplant recipients' accounts, with attention to identities and social re-positioning in relation to dominant discourses of organ transplant and their shifting relationships with health service providers. The study was designed to focus on the time period when transplant recipients transition from a paediatric hospital to an adult healthcare facility. As the study progressed, however, unanticipated issues emerged from the study and it became evident that the hospital transition process was not the sole challenge that confronted study participants. What was highlighted in this study was the concurrent demanding life circumstances of various social fields as transplant recipients transitioned from adolescents to young adults. To this end, and in keeping with Bourdieu, I further explored individuals' characteristics within various fields and incorporated interview data wherein participants talked about their past and present experience as a transplant recipient. Current relations with healthcare professionals and parents, and the complexity of study participants' positioning within a field, as well as the relevant forms of capital were iteratively analyzed.

The results of the study have been divided into two chapters. Together they fulfill the study purpose and provide interpretive results that draw on the study's theoretical underpinning. The focus of data analysis was to explore participants' time from youth to young adulthood, and to provide a rich description of individuals' characteristics, their lifestyle, life circumstances, and

relations of various social fields. The first chapter focuses on the onset of illness, when participants were first diagnosed with end-stage heart disease. Quotes from participants captured their uncertainty and fear during this turbulent time. Next, I explore how illness and treatment affected participants' social practices within various social fields, fostering and/or impeded the accumulation of various forms of capital. Finally, I discuss everyday routines of the paediatric clinic environment where recipients were imbued with a practical habitus of passivity and participants' ultimate transition to an adult healthcare facility. What is being discussed is that participants felt that the transition to the adult healthcare clinic allowed them to be age appropriately repositioned as adults in charge of their care. This illuminated that transition programs were provided in a field where youth were accustomed to passivity and as such they were not involved and engaged in the process. Included in this discussion is the formation of habitus, how recipients carry themselves and perform actions and acquire various forms of capital.

The second discusses 'fields of struggle': transplant recipients' relational positions within other dominant fields. First, I outline participants' relational position within the hierarchy of the dominant field of healthcare. I discuss participants' adherence with medical recommendations, a key symbolic capital that ensures them a relatively favourable position within the dominant discourse of illness self-management and responsibility. And, ultimately, failure to embody medically recommended practices is inextricably linked to struggle within the healthcare field and symbolic violence. Next, I demonstrate that the peer based social field of young adulthood provides few opportunities for the chronically ill to accumulate capital through valued activities that formulate normative "ways of being". I explore the self-representations of most participants' as living "normal" lives. They conveyed living with illness as normal, which then became a

strategy for negotiating favourable positions, particularly given the push in the healthcare field of personal responsibility and self-management. Finally, I discuss participants' reluctance to share their transplant experience with others, purportedly since no one could understand what it is like to live with a transplanted heart and the ongoing suffering that result from it. The risk of alienation or marginalization, of not being a "normal" young person, informs recipients' logic of practice.

These ideas are then taken up in more detail in the Discussion Chapter, where I will discuss the results of this study in terms of a) belonging and health, b) social transition: from youth to young adulthood, c) fields of struggle (as portrayed within the literature on medication adherence), and d) symbolic violence and embodiment of a dominant social order within the healthcare field.

In this study, all participant names are pseudonyms. Quotations presented are chosen as succinct representations of the issues or practice under discussion. Some participants are quoted more frequently than others because they verbalized common experiences or practices of study participants in a concise and articulate manner that lends itself to quotation more often than others. All quotations and descriptions, unless otherwise indicated, are intended to be representative of the larger group in this study and the types of practices and positioning being explored.

I/a. Life put on hold: becoming ill

Introduction

Participants described the process of being diagnosed with their illness. They talked about the complex and profound symptoms they experienced, including having their failing heart function supported with a mechanical device, while waiting for a suitable heart. Becoming ill

disrupted the previous flow of everyday activities, which cut across other fields. All of the participants had to miss school due to their complex illness conditions. Being ill altered relationships with friends and family members and for one participant meant the end of a romantic relationship. Following the transplant, returning back to school and progressing through educational programs was expressed as a source of capital. Participants talked about receiving support from teachers in order to graduate from school. In school, however, participants described limited opportunities to accumulate social capital in the form of friendships with classmates.

Results

Ingrid talked about the abrupt onset of her disease and her diagnosis with heart failure as something very unexpected given that she was a healthy child who had regular check-ups,

Ingrid: ...but, uhm, I was a healthy child, and I had regular check-ups and nothing was wrong, and just one day I started vomiting, and, uhm, my parents they took me to the hospital... first, like, the walk-in clinic... [...] then they took me to a hospital and they found out that I had an enlarged heart.

Similarly, Peter experienced a dramatic change in his life when he was diagnosed with heart disease at the age of 15. Within a few days he transitioned from being a healthy adolescent to a person needing a mechanical assist device (Berlin Heart) while waiting for his transplant.

Peter: I was just like working and hanging out with my friends [...] Like, three days before that ... me and my buddy biked up to the ... Mall and back, which is like a three and-a-half hour bike ride there. Yeah, and like the next day I was working and the day after that I was in the hospital. [scoffs] I felt, like, a little sick, like, kind of like 'flu-ish, but like I went to the clinic to take a look at it... that's how I got found... ...it was like I just went to the clinic, and then they sent me to the Royal Victorian Hospital... ...and then from there a helicopter to Sick Kids. [...] ... there was fluid built up around, like, my lungs and stuff, and then my heart looked a little large [...] ...then they explained everything to me when my parents got there...I had to get a transplant. [...] I was in the ICU for a bit [...] ...I was on the Berlin heart, too.

The pictures below are generic pictures of a Berlin Heart (artificial heart) and a young boy with the implanted device. They have been included here in order to illustrate the very advanced form

of medicine and technology involved in sustaining someone's life. The picture to the left is a display of a Berlin heart, illustrating the kind of technology that is placed in a young person's body. The picture on the right shows a young person with the device in place and all the external machinery required running the artificial heart. For many study participants becoming ill meant to be exposed to very advanced high-tech medicine in order to live long enough to receive a heart transplant.

Ken also required a mechanical assist device. He was hospitalized for a few months while waiting for a suitable heart to become available. He describes this unexpected experience as being like a partial cyborg.

Ken: First I went to Sick Kids. [...] And when I was there I got the LVAD, which is a heart pump. [...] Something I never... I didn't expect. ...And I had it for about five months or so. [...] It's like partial cyborg...having a mechanical heart pump...to keep you alive [...] It took a while to get used to.

These were remarkable shifts that included drastically altered physical sensations and new social positions within unfamiliar health care fields.

Celia referred to the time when she first became ill as a life-or-death situation. She experienced sudden onset of flu-like symptoms, extreme fatigue and weakness. Healthcare

professionals had difficulties diagnosing her worsening heart condition. Celia felt very sick and not knowing what was wrong with her was a very difficult process for her to go through.

Celia: I was 16, 16/17. [when I had my transplant][...]... it felt like a life-or-death situation, just trying to, you know, strive, trying to keep strong. But yeah, there was a lot going through my mind. I was just trying to stay strong for my family, because I have brothers and sisters, right? [...] I wasn't sick for a long period of time. ... I thought I had stomach 'flu so I went to the nurse or the doctor's, my mom took me there, and the nurse was saying that, you know, that I should drink or whatever, like, maybe because I'm probably dehydrated My mom did that and, like, after she gave me all those fluids I just felt worse. [...] Like, I just felt even more sick, and I was just like I couldn't keep nothing down, and my mom was like, "you know, you have school, you have to go to school." I'm like, "Mom, I don't know what it is, I'm honestly sick. Like, I don't feel healthy at all." Like, I was just so weak, like, I couldn't get out of bed, like, and all I did was throw up. ... like, I just felt weak, like I couldn't help myself, you know? It was just very hard, very hard process to go through. I was crying because I got so overwhelmed because, like, at that point I felt like I knew it was something serious, you know?

After Celia was diagnosed with heart failure and admitted to the hospital, her heart conditioned worsened and she was transferred to the intensive care unit.

Celia: So it was just like, "Wow," like, "This is for real." [...] ... I was in ICU, like, I was that sick. Like, I was in a room full of other babies and stuff like that because, like, I have to be monitored 24x7 because my condition was just that bad. I think I was at, like, Stage IV or something. [...] Couldn't be by myself, couldn't even have my own room or nothing.

Eventually, Celia's heart function decreased so severely that she needed to be bridged with a mechanical assist device (Berlin heart) while waiting for a heart transplant. Her frustration with her worsening condition became palpable when she described how a suitable heart became available; she was ready to have her sick heart "ripped out of her".

I have these scars [from the Berlin Heart] right here. ...so it's like I've had the Berlin for a little bit and then 16 hours later, bam, they go, "We have a new heart for her, does she want it?" blah-blah. I'm like, "Yes! Like, I want to, like, rip this out of me now." I just wanted to go home, I didn't feel like I... felt like I'd been sick for so long. Even though four months doesn't seem long but it seemed like forever.

Many participants in this study shared Celia's experience. Most of them experienced abrupt onset of nausea, vomiting and flu-like symptoms. It took time for healthcare professionals to

provide an appropriate diagnosis, and frequently participants reported not being taken seriously by their parents. Adults, at times, interpreted their children's symptoms as a performance in order to skip school. All study participants described commonalities of uncertainty, fear, and a life put on hold.

In contrast to participants who had no prior indication of heart disease, some study participants were diagnosed with a cardiac condition at a very young age that frequently required surgical interventions. Anna and David both had multiple surgical procedures throughout their childhood leading up to their heart transplant. Although their underlying illness conditions are very distinct, both participants experienced progressively debilitating symptoms that impacted their everyday routines.

Anna: My first heart transplant I was five months, and my second heart transplant I was eight years old, ... and my kidney transplant I was fifteen, in 2008. [...] Yeah. 1994. I was getting sicker and sicker and I couldn't... [...] Yeah. Well, I couldn't lay on my back and stuff, so my mom got me checked out and they said that I needed a heart transplant because my heart was too big. I don't remember the... the names of the diseases... ...but I just know, like, what was wrong.

David: When I got my transplant...I was 13. [...] I went in for a pulmonary valve replacement, and during the time prior to that I had something called the Ross Procedure done... ...and during that surgery the doctor had kinked the coronary arteries and, so I was having problems, I guess, ten months until they realized that there was something wrong, and I was back and forth to the hospital about seven times and they kept sending me home and telling my mom that I just wanted to miss school and that, and that I wasn't really sick. [...] And then ... they realized I was really sick and they're like, "Oh, you need surgery right away." ...so the heart was dying over that ten-month period. And then once they put the new pulmonary valve in that was leaking they did my chest back up and they were taking me out of the operating room and my heart died.

David continued to talk about his progressively worsening heart condition while he was in hospital. Like other youths in this study, he also required a mechanical assist device after "his heart died", in order to keep him alive. David, however, also highlights that not all individuals on the transplant waiting list receive a heart transplant. He explained that his declining medical

condition was possibly causing permanent brain damage, at which point further treatment would be deemed futile and the healthcare team would turn off all live support in order to let David die.

Fortunately, after a short but turbulent period a suitable heart was found for David.

David: Yeah, and then for four days I had my chest open and I was on a machine called ECMO...which pumps the blood through your body backwards... [...] ...just to send blood to the other organs and that, and my chest [sic] was just pushed to the side not beating four days, and they had sponges all in my chest. [...] Yeah. And twelve hours prior to them having to turn the machines off – because I would have had brain damage from, like, lack of oxygenated blood and stuff like that, and all the bags of blood I was going through... [...] ...uhm, yeah, twelve hours before they had to turn the machines off somebody got into a car accident in Calgary and they flew their heart in. And when I woke up I thought I was only asleep for two hours and it was two and a half weeks later that I woke up out of a coma... [...] I thought my mom and dad were joking with me at first, they're like, "Yeah, you got a new heart," and it's like, "Are you serious?" like, I didn't believe it at first...

Similar to what David had experienced during his stay in the intensive care unit, the picture below shows a young person on ECMO who has serious medical conditions with impaired heart function. The ECMO machine does the work for the person's heart and lungs and maintains blood flow and oxygenation to the vital organs (liver, kidney, brain). The function of these organs is maintained in order to keep the person alive while waiting for a heart transplant.

I/b. Life put on hold: recovering from heart transplant

All of the participants had to miss school due to complex illness conditions. They did not describe missing school as a concern. Some participants repeated classes, while others received additional support in order to keep up with class content.

David: ...when I got my transplant I was in grade 8, and in the summer I had, like, a little bit of a tutor, but I graduated, like, because before I went in the hospital I did a bunch of work because I knew I was going in for the surgery – it was scheduled already – so my teacher gave me an assignment and I brought it in prior to going to the hospital, and I got an A on it and whatever, and so I graduated, like, they graduated me from grade 8, and then I had all summer to, like, get better.

Stephan: ...so what happened was I wasn't in school a lot of the time. This is when I was in grade, I think, 11, when I had the transplant, so it was before that I was in and out of the hospital being home sick, and then my teachers actually really, really liked me, and my school really, really liked me, that they home-schooled me during my operation. This way I could have... I could graduate with my friend...so everyone was helpful in that sense.

Following heart transplant, all study participants were able to return to school and either completed their program, or they are currently in the process of finishing their training. Being removed from school, however, provided fewer opportunities for individuals to be with their friends and therefore severely impacted the possibility to form peer relationships.

Supportive efforts of educators ensured that participants continued to accumulate educational capital so they could maintain position within their peer cohort in school. This may have been focused on cultural/educational capital but was less successful in maintaining peer social capital (they lost friends and became isolated because of illness in some cases). Peer tensions were many.

Participants shared that classmates thought that they are pretending to be ill in order to avoid going to school. Anna spoke about a time prior to high school when her friends questioned her about her absenteeism. She found this misunderstanding extremely difficult and it only

improved after she got to high school. Ingrid explained that she was always seen as different in school because her body looked different and she frequently missed class. At one point she even required a walker due to a spinal injury, further highlighting to her classmates that she was different. Not being seen as ‘normal’, she was continually bullied by her peers.

Anna: ...so I missed more school, too and, you know, students thought too that, “Oh, you know, you’re missing school for nothing,” and, you know, I was just like, “What are you talking about? No, I’m not, I was at home, I was sick,” or at the hospital even, and... yeah. And that time it was more difficult for that, but since I’m in high school, uhm, things got easier because they understood more of my situation and, like, when I missed a lot of school, uh, when I was in ninth grade – that’s when I got my kidney transplant –and I’d just begun ninth grade, and I missed, like, three months of that, but they, you know, they understood, they didn’t, you know, care. ... they didn’t worry about that, they were just like, “Oh, well, get better and we’ll sync... like, we’ll talk about that when you come back”.

Ingrid: I looked... yeah.[...]...uhm, like my face, my torso was much...was really big. [...] I... I was bullied because I was bigger, because I missed a lot of school, because I was different there. So that was my experience in... in middle school. And then in grade eight I had a fracture in my spine and so then I used a walker. So I was always...always somewhat different, even physically.

End-stage heart disease and the wait for a transplant disrupted everyday activities and relationships with friends and family members. As participants became ill they had fewer opportunities to be with their friends, which ultimately resulted in loss of the social capital of peer friendships.

Ken: Yes, I was in grade 10. [...] Uh, I was there for the first three months or so, then, I don’t know, my heart just started to give out, so I was not able to go [...] I mentioned it [needing a heart transplant] to a few friends that are close. [...] None of them from my high school came to visit me ... They were the ones I’d known for some years.

Celia: Like, I’ve had friends before this. Like, I mean, when I was sick at the time and, like, I’m looking back now and they’re not here for me so, you know, it’s just like, you know, you always have your family with you no matter what, so I just... I’m grateful for my family, I’m grateful for my mother and my father, they’re very, very supportive people and they always drive and push me to do the best because they always want better than what they had, you know, and they’re... they’re really good parents.

Gail: ...to say, "Okay, you have to go down to Toronto now." [chuckles] It was scary because I didn't really know what to expect. I knew I was going to be living in Ronald McDonald House [hospital-supported accommodations] but I didn't know how long, how it was going to be, anything really [...] Well, I don't really make friends that easily.

Participants demonstrated sadness over these losses, but at times were able to establish closer relationships with their parents. Concomitantly, families who lived too far from the hospital were required to move to the city and stayed in hospital-supported accommodations. For these participants the significant distance from home frequently meant a loss of relationships with their peers. And one participant started her interview by talking about that the loss of her health also meant the end of her romantic relationship.

Gail: I was seventeen when I had my transplant. ... I was in an upgrading class at the time and, uhm, I kind of just met someone new... [...] ...so it was kind of not a great time for me.

Summary

Illness disrupted everyday activities of participants. In this study, for some individuals the onset of illness was very abrupt and unexpected. For others it has always been in their foreground with surgeries starting at a very young age. Illness, however, was always unsettling and impacted everyday activities. It continuously signified a life put on hold. 'Life on hold' was observed throughout various fields as it impacted participants' daily activities. For example, all participants missed school, and with the help of teachers they worked hard to continue progress through educational programs. Some were bullied at school because they were perceived as being different and therefore did not belong to the group. Finishing school was important for all participants and represented an important cultural capital; its continued accumulation was strongly supported by adults in their lives. For most of the study participants, however, frequently missing school and being an outsider provided few occasions to connect with their

peers. This provided limited opportunities to establish social capital and build lasting relationships, yet parents and teachers rarely addressed this problem.

II. Everyday routines in the clinic and at home

Introduction

Growing up with a heart transplant and receiving ongoing life sustaining care at a paediatric healthcare facility shaped habitus and provided participants with a sense of how to act within the hierarchical structure within the field of health care. Everyday routines of the clinic and the social interactions between transplant recipients, healthcare providers and parents were mapped on the bodies of young adults. Their bodies were continuous with and symbolic of their identities as transplant recipients and patients. To understand habitus, attention needed to be paid to how recipients carry themselves and perform actions. Adolescent transplant recipients relied on parents and healthcare providers to manage their medical routines. Participants described their limited knowledge of medications and possible negative transplant outcomes. Although every participant had experienced graft rejection at some point, requiring additional antirejection medication and at times admission to hospital for more aggressive treatments, few had deeply reflected on potential negative disease sequelae. While receiving care at a paediatric healthcare facility adolescents were sheltered by healthcare providers and parents. Participants conveyed acceptance of the taken-for-granted routines of the health care field and outwardly endorsed these practices in their daily life.

Results

Living with a heart transplant entailed frequent visits to the paediatric transplant clinic for check-ups. The clinic was hierarchically structured and imposed its unspoken rules of how a young patient ought to behave during clinic visits.

Anna: ... for [paediatric]heart transplant clinic, ... they would sign you in and there would be, like, a playroom where you would wait...and there was, like, tons of other kids, too. ...and then... I think it would be a volunteer or... not a doctor but... how do you call that? Anyways, a nurse or something, they would take you. [...] Yeah, and then you would go to your room and they would scale you and all, like, over here...and you would wait for the doctors and... yeah, that's it. [...] Yeah, like in a room like here, we would just wait for the doctors. We... I don't know. You know... not the real doctors, but the... Yeah, the fellows. Yeah, the fellows would come in first to check the medications we were taking and all that stuff, and if you have any questions, and then you would wait and then the real doctor would come in and check you.

Peter: Yeah. I remember at, like, Sick Kids me and my mom were usually waiting there, or me and my dad would usually wait there for, like, an hour, like, forty-five minutes before we got in places...

The pictures below illustrate the paediatric hospital areas that Anna and Peter described during the interview. The photo on the left shows the reception desk where recipients sign in when they come to the clinic, which is centrally located and brightly lit. The picture in the center and to the right captures the waiting area, with the last image providing a view of an examination room where recipients wait to be seen by healthcare providers. Even though the reception area is

very typical of a hospital setting, what is clearly visible from the rest of the illustrations is the hospital staff effort to create a child friendly environment. They do this by providing toys and having storybook like paintings on the wall. In a later section of this chapter, I will further

discuss how participants miss the colourful environment of the paediatric hospital, but highlight that there is a particular sameness to both clinic environments.

Clinic structures and their daily routines shaped individuals actions and manners. Everyday routines and characteristics of the clinic are taken up by recipients and are visible in the form of habitus. Habitus was best observed when paying attention to participants' dispositions and behaviours in the clinic. On arrival at the clinic patients signed in at the front desk and were eventually taken to an examination room, where they waited patiently for a physician. The clinic was setup and functioned in a particular way that provided the most convenient way for healthcare providers to examine and interact with recipients. Coming to clinic, therefore, always entailed waiting for long periods of time before being seen by a healthcare professional. In addition, participants described a particular hierarchical structure among physicians, which was based on various tasks performed. All physicians at the clinic are doctors; however, physicians in training were seen as "not the real doctors". This highlighted individual relations participants had with their physicians.

Some of the study participants had multiple medical concerns and were required to see other healthcare professionals in a variety of clinics throughout the hospital. Managing numerous clinics visits left some recipients defeated, as they expressed frustration about their poorly coordinated clinic appointments.

David: I think their transplant floor is really good. Like, but out of hospital, like, the care's a bit different, like, I guess they don't correlate with other aspects of the hospital – like, if you... like, I'm diabetic as well...I also have renal issues [...] and problems with my liver – so yeah, the hospital there they didn't really correlate with each other so they would book me for an appointment to say, "Let's go see the endocrinologist on this day," and then the transplant people would want to see you but they'd book you their appointment at the same time... at, like, on the same day or something. So, like, one team didn't talk to the other team and you'd have an appointment and you're supposed to be at another appointment at the same time.

These inconveniences positioned patients' time as secondary to the structures of the clinic and practices of health providers.

All participants developed strong relationships with their healthcare providers at the paediatric hospital. Being cared for in a friendly environment was important for transplant recipients.

Anna: ...Yeah, they [doctors and nurses] were really nice. I got, like, attached to them and stuff. They're friendly, like, you know, like with kids, and not like strict and stuff, but...yeah, they're... they were also strict, but I mean not to the point where they would be mean, you know? Yeah, they were friendly, yeah.

Ingrid: ...my experience with the doctors ... at Sick Kids...was always great. They were always so warm...

Transplant recipients thought of themselves as kids - like all other kids - who are allowed to stray off the beaten path, while at the same time recognizing that a certain rigor to 'being a good transplant patient' was not only required but also endorsed. Participants also established a particular hierarchy among doctors and other healthcare providers. What was seen as most important by participants was how physicians interacted with them, which was followed by how they were treated by nurses. Recipients used terms like caring, warm and friendly to describe positive relations with their healthcare team.

During clinic visits healthcare professionals frequently only addressed participants' parents to talk about any medical concerns. Recipients reported that they were troubled that such actions made them miss important medical information. These hierarchical communication structures shaped young transplant recipients' habitus, the acceptable behaviour in the clinic was to quietly sit back and let parents and healthcare professionals talk about their medical concerns. Kids got used to the clinic routines, took few initiatives to voice any questions or concerns and

incorporated these clinic structures into their normal clinic practices. Young transplant recipients' routine clinic visits evolved a practice of passive dependence on parental caregiving.

Peter: Yeah because everywhere... like, or at Sick Kids they were always talking to my parents and stuff and, like, not really paying... like, not really talking to me, so I didn't really get that much of the information.

Anna: ... most of the time [my mom would come to clinic], yeah. Yeah, well I was used to it [clinic routine] so I didn't really ever have any questions...and if I did it was because my mom wondered about some things...

The pictures below show Anna during the interview. As it is difficult to change one's disposition in a very familiar location, and the interviews for this study were all conducted within the hospital setting, Anna's acquired habitus of interacting with healthcare providers was still felt during the interview. She attentively waited for me to ask a question, enthusiastically provided a response, which was followed by a pause where she lowered her head and waited for the next

interview question. Even though at the beginning of the interview participants are encouraged to talk about anything that they feel is important for them, interviewees followed a particular rhythm that might be reminiscent of their passive habitus during earlier clinic visits.

Similarly, one study participant was frequently accompanied by his mother during clinic visits, even though he preferred to go for his regular check-ups on his own. At times when he

was able to go by himself, healthcare professionals told him that it would be better if one of his parents would be present during clinic visits to make sure no important instructions were being missed.

Ken: Yeah, at first it was both my parents. [...] And most of the time it was with my mother. Uh, [pause] I prefer[to go to the clinic] by myself. Basically when I missed something...the doctors were saying I wished one of my parents were there.

The picture above illustrates Ken during the interview. He provided very short and abrupt answers throughout our meeting and spoke with a soft, nearly inaudible voice. A similar passive disposition during clinic visits might let healthcare professionals assume that he could miss important medical information. Interestingly, he came to clinic wearing a t-shirt that read “skilled in every position”, which might suggest a juvenile disposition. Even though he longed for more authority and independence over his medical care, as demonstrated in his quote, he was not able to successfully portray this to the team.

As the clinic structures shaped participants’ habitus, their actions and dispositions were carried over and reproduced in everyday situations. Established clinic routines placed parents in charge of their children’s medical needs. Similar behaviours were carried over in everyday routines at home. All medically related tasks were performed by parents, so adolescent transplant recipients took on limited responsibility for managing their routine medical

needs.

Anna: ...for appointments and for, uhm, questions my mom had the phone number and usually she'd be the one who would call it because I think she was so used to her being, like, the one that would do everything that she got [chuckling:] used to do it.

Ingrid: ... I think it's common, when you're sick as a child you don't really know what's going on... [...] ...and my parents, with their best intentions have sheltered [me]...

For one participant it even meant that her father took on a much more active role in making sure that her daughter is on the right medication. She described this particular event with a strong sympathy for her father who was so determined to research the latest medical treatment in order to make sure that she is receiving the best possible care.

Ingrid: ...uhm, like, I remember, uhm, when I was on cyclosporine my father, he really fought with the doctors, and he would work and he would spend all night researching, and finally they... they... like, he would fight with every doctor to get me off this medication, so he was really involved.

Managing routine medical needs includes adherence to strict medical routines that if not followed can potentially lead to organ rejection. All of the participants in this study – in one form or other –experienced graft rejection, requiring additional medical interventions. All youth in this study approached rejection very rationally, as an event that happens to transplant recipients, which is being managed by healthcare professionals and ultimately improves with new therapy. None of the recipients openly discussed their reflections about potential detrimental outcomes, where rejection ultimately progresses to complete organ failure. Peter had experienced graft rejection immediately following his heart transplant. Moreover, he continued to experience episodes of rejection throughout his youth. Peter described that at times he had trouble remembering to take his medication, which was most likely the reason why he experienced frequent episodes of rejection. Even though he understood the potential consequences of not

taking his medication, he did not discuss during the interview his understanding of how to better manage essential medical necessities in order to avoid potential future organ rejection.

Peter: So uhm, yeah, they put the heart in, and I was in rejection for a while and I was in and out of the hospital on a bolus of steroids and whatnot to combat against the rejection, and then they got me on the new medication that came out ...

Peter: If I don't take it [medication] then that's usually what causes rejection. [...] ... I had one, like, a while ago [prior to my transition to the adult clinic] and, like, I wasn't taking my pills properly and then that's why I had rejection. [...] Yeah, like, because I have to take it before I go to school in the morning, and sometimes I'd leave and then I'd forget, and then I'd come home and take them at night, but I didn't... like, yeah, sometimes it just slips my mind, I just forget it.

Summary

Frequent clinic visits, long waiting times and the everyday routine of the paediatric clinic fostered a passive and unassuming habitus in young transplant recipients. Actions and behaviours in the clinic were taken up by transplant recipients and reproduced in everyday routines outside the hospital. This was observed in interviews where recipients described little interest in taking on medical responsibilities at home. Parents were in control over participants routine medical care and took on the responsibility to manage their lives. In the end, habitus can be best observed when linked to capital. In this study, participants confirmed that they had limited opportunities to develop various forms of capital. Participants had few opportunities to develop social capital within the clinic, since their parents conducted most communication with healthcare professionals during appointments. Cultural capital in the form of medical knowledge, like understanding potential negative transplant related outcomes was limited due to inadequate engagement with healthcare professionals. It is conceivable that a lack of those capitals put participants at a certain disadvantage as they moved towards young adulthood, with the expectation they would assume more responsibility for their own care.

III. Youth, young adulthood and the process of transition

Introduction

At age 18 transplant recipients were transitioned from paediatric to adult healthcare facilities. Participants were prepared for this change in a variety of ways including one-on-one educational sessions, review of informational pamphlets and webpages. Healthcare professionals aimed to increase recipients' knowledge about medication and possible negative transplant outcomes, and to provide an opportunity to meet members of the new healthcare team by walking them through the hallways of the adult clinic. This was seen as helpful by participants and provided familiarity with the physical layout of the new clinics. Most participants described the transition process as well organized and commented on how friendly and warm healthcare professionals were in the adult transplant clinic. Alternatively, few study participants felt that they received not enough information, and for one participant the provided reading material was distressing. In this case, not having sufficient guidance by healthcare professionals in how to interpret the medical information was anxiety provoking for the participant.

Results

Below are some of the teaching materials used by healthcare providers to prepare recipients for the transition process:

MyHealth Passport and Bookmark

- A portable, customizable, wallet-sized document created by a patient and their provider
- Encourages paediatric patients to gain ownership of their health information
- Can be used free of charge and does not require any downloading

www.sickkids.ca/MyHealthPassport

Transition Reminders

Good 2 Go Website

A few study participants explained that they were part of a transition program. The goal of the program was to familiarize recipients with the routines of the adult transplant clinic. Recipients had an opportunity to meet members of their new healthcare team in order to alleviate potential anxiety about their expected transition to an adult healthcare facility. In the following segment Peter describes how these transition programs were conducted and the positive impact these information sessions had on recipients.

Peter: Well, like, they had a whole presentation that they did here. They [healthcare professionals] brought everyone who was turning 18 over to this hospital [adult clinic] and they did, like, a big tour and we got to meet everybody. Like, so it wasn't like when you come in your first time, just like a stranger that you're talking to...so you kind of get comfortable with it and stuff, first. [...] ... they had, like, a whole slide show, and they showed us all around, like, the floor and everything. Yeah, and we got to meet, like, most of the people that we'd be dealing with...and stuff like that. It was really... I thought it was really helpful.

Other study participants reported that they were not part of a transition program. These recipients attended one-on-one educational sessions with a nurse practitioner who informed them

about the new clinic environment. David is a participant who had met with a nurse practitioner; in addition, he was setup with a mentor who was a transplant recipient and had adapted very well following his transition to the adult clinic. David commented:

David: Actually, no. I wasn't in a [transition] program but I had somebody come and visit me when I was at Sick Kids and they told me basically how the program kind of worked around here, ... and I also met another person from the program here name was Tina and she actually met me down by the [coffee store] by my house, she came out and seen me, and she talked to me a little bit about the differences from here[paediatric hospital] to there [adult hospital].

Tina also met with a nurse practitioner. She was ambivalent about these meetings since important information about routine medical procedures was not provided. Tina learned from her uncle, who also had a heart transplant, that cardiac biopsies in the adult clinic are not performed under general anaesthetic, which was the standard approach at the paediatric hospital. She felt that the nurse who prepared her for the transfer should have provided such important information. She commented:

Tina: ... I was switching over soon...so I think it was one of my clinic days, um, one of the nurses from here went over to Sick Kids to see me and she basically just talked a little about what it was going to be like and, well, to be honest I... I think she should have [chuckling:] said a lot more. [...] ... I mean, in Sick Kids their biopsies are completely different. She didn't say anything about that. I actually had to learn that part from my uncle. He also had a heart transplant. [...] Well, in Sick Kids they usually put you to sleep, so the IV and all that, but over here [at the adult clinic] they just... you just kind of [chuckles:] get on the table and they do it. [...] Uhm, so yeah, if I didn't learn that I would have been going to biopsy thinking they do the same thing as there and I'd probably be very confused and then [chuckling:] very nervous.

Her words highlight what several participants in this study commented on. They reported that their healthcare team did not inform them that cardiac biopsies at the adult clinic are not performed under general anaesthetic. Participants frequently did not know about this procedural change until they had their first biopsy in their new clinic environment and reported being very confused and anxious about this change. Recipients quickly realized, however, that a decreased

use of sedation also meant that they would not have to stay in hospital for the entire day to recover from their procedure. Frequently, recipients could be released from the hospital within a few hours after the procedure was completed. This was seen as an advantage as it allowed participants to return to their everyday activities with very little downtime following the procedure. Potential loss of capital in the form of workplace or school absence was avoided.

Participants did not always embrace receiving in depth information about what it means to live with a heart transplant. Ingrid explained that she was given a booklet to read that informed her about potential negative transplant related outcomes. She read the booklet by herself and was discouraged and shocked about the provided information. She had this to say:

Ingrid: I remember when I went from Sick Kids to Toronto General they, uhm, they gave me this book which, like, I guess like with a Duo Tang, like, something very kind of simple...with, you know, like I guess it might be a hundred pages, like something basic...and I was looking through this book and I was... I guess I knew approximately these medications have some pretty severe side-effects, because I mean, like, they're so important for me to live but with any... so I just I remember being so shocked, uhm, when I... when I saw that I had, you know, three times the chance of getting so many different kinds of cancers...and there was, I guess, a page in the book that said, uhm, that my pregnancy, if I were to get pregnant it would be, uhm, it'd be sketchy, you know, it'd be, you know, life-threatening for me...[...] uhm, it was just... it was shocking to go through, because I never... no. Yeah, and so it was kind of like, "Oh, my goodness, this is what it means."

While health providers were responsible to provide transplant recipients with information about medication side effects and negative health outcomes, transplant recipients did not always interpret medical knowledge, a form of cultural capital, as important. In the case of youth like Ingrid, this lack of interest seems continuous with a deeply inculcated habitus of passivity in matters of health decision-making. Ingrid was sheltered by parents who protected her from potentially distressing information about what it means to live with a heart transplant. In the above passage it is evident that recipients' acquired practices of passivity and health professionals' educative goals at the time of transition create a site of intense struggle.

In general, participants reported that healthcare professionals used a variety of methods to engage participants in preparing them for the transition process. Celia and Peter were both encouraged to complete a computer based educational program in order to prepare them for their pending transition to the adult health care facility. The educational package also included a “personal passport” that documented the transplant recipient’s pertinent medical history. The passport could be carried to clinic visits so the required medical information was available so participants would not have to rely on memory alone. The following narration builds on this conflict between recipients’ apathetic response to the transition process and healthcare professionals’ urgent interest in preparing informed consumers of adult healthcare.

Celia: Uhm, I don’t really remember a lot [about the transition], but I just remember, like, You know, like, I don’t...[...] I think, like, when I turned 18. [...], I remember they, uhm, they gave me, like, this white card and, like, had my information of, like, going through a transplant or whatever and, like, cardiomyopathy, like what I had and whatever and whatnot, like, and they made me... like, it was on a white card...just to, like, you know, know my information about myself and my health and stuff like that, so when I come here [to the adult clinic] I, like, I know a little bit about what I’m talking about. [...] Yeah, I think there was this nurse, she was sitting down with me, she was just kind of doing this computer stuff with me. [...] Yeah, it worked. I mean she made me under... understand, whatnot.

Peter: Well, they gave me – what was it called? – it was, like, a... I don’t remember what it’s called, but it’s kind of like a thing where you go on the Internet and, like, before you come for your first visit you fill out, like, everything that you have...like, your passport, I think that’s what it’s called. Right. Yes, I think that’s what they’re calling it. [However] I didn’t actually get the time to fill it all out because it was really long and I had [chuckling:] lost my page, so...

A number of participants commented on the fact that they were not prepared by healthcare professionals in any particular way, other than the reassurance that the healthcare professionals in the adult clinic were friendly and approachable. Participants expressed trust in their paediatric team and therefore were comfortable with their impending move. Anna had this to say:

... in clinic they were just saying, like, “Oh, well, good luck with everything, and they’re nice too, don’t worry...” so I was just like, “Okay.” Well, you know, I trusted them, so I took their word for it.

In general, it was common for study participants to describe the transition process as organized and uneventful. Stephan described how healthcare professionals prepared them for the transition process; however, participants frequently reported how simple it actually was for them to move from a paediatric hospital to an adult healthcare facility.

Stephan: I don’t know. I don’t think... they may have given me something to read but I find it’s... it’s a hospital, it’s not really... there’s not much...to... like, I don’t know, it’s... it’s a simple transition, it’s not... it’s not that complicated. It’s one doctor to another doctor. I think I came here [adult clinic] once...and that’s it, and then it just all happened and it was all easy.

Below are pictures of the waiting room in the adult transplant clinic and a clinical examination room. Most certainly the lack of toys and drawings on the wall make this place look much less child friendly in comparison to the paediatric hospital. It is the functional ability, however, and the layout of the examination room that in essence are very similar to the paediatric clinic. It is therefore understandable that some of the participants talked about the sameness between the paediatric and the adult clinics.

Summary

Study participants reported that healthcare professionals prepared them in a variety of ways to alleviate uncertainty and potential anxiety over their impending transition. No single teaching modality was seen as most helpful. Some participants voiced concerns of not receiving enough information, but not knowing what to ask; others were overwhelmed and distressed by teaching material that focused on potential negative transplant outcomes. A few participants even thought of the transition process as something very simple, for example, leaving one healthcare team and joining a different team was just a change in location and required little adjustment from the participants' perspective. In general, participants described the transition process as well organized and commented on how friendly and warm all healthcare professionals were. They *perceived* the adult clinic environment to be very similar to their paediatric hospital. As I will demonstrate in the following section however, participants entered a new hierarchically structured social field that functioned in familiar ways but with important differences. To this end, innovative teaching approaches might be needed, as the findings illustrate recipients' habitual apathy within the health care encounter. Healthcare professionals' adopted various teaching strategies to inculcate a new, more consumer oriented stance in the transplant recipients at the time of transition. The potential struggle between fields, and ultimately a struggle to inculcate a new habitus, provided limited opportunities for participants to acquire positive capital within their particular fields.

IV. Rite-of-Passage

Introduction

Having transitioned to a different hospital and therefore having entered a new field, participants' ingrained dispositions (being a paediatric transplant patient) were out of place and

led to a shift of their particular habitus. Participants replaced previously acquired behaviour with practices shaped by their new healthcare field, conducting themselves in a manner that was expected of an *adult* transplant recipient. Most participants stated that they were ready to transition at the age of 18, with a few commenting that they felt ready to move to an adult clinic at age 17. Being cared for in an adult hospital meant that participants perceived themselves as adults and felt that this was the right time to take on the responsibility of looking after their own medical needs. Taking on more responsibility in the form of (re) ordering medication, booking clinic appointments, coming to the hospital for biopsies without a parent, and talking to healthcare professionals about their medical concerns was expressed as a form of cultural capital. Most recipients demonstrated a transition from a passive habitus to a more active role in managing their medical needs. They acquired more knowledge about handling their condition, and as such were able to demonstrate better self-care. When transplant recipients were able to take on what was expected of them in the adult transplant clinic, they demonstrated a certain “feel-for-the-game”, recognition of appropriate behaviour, inculcated through habitus.

Results

When study participants were asked if eighteen was the right age for them to transition to the adult healthcare facility, most of them believed they were ready at that time to navigate the transition process. All participants reported, however, that there was no discussion between the healthcare team and transplant recipients if they would have liked to transition at an earlier age, or potentially even stay longer with the paediatric team. Peter pointed out that it was the paediatric transplant team who determined the time for recipients to transition to the adult clinic.

Peter: So it was like, “Okay, you’re turning 18, this is the time for you to go.”

A few participants felt that they would have liked to transition at a younger age, but were never provided with an opportunity to discuss a potential transition at an earlier age. David had this to say:

David: Yeah, I think so. I think maybe I could have came over at 16, 17...

Having transitioned to a new healthcare environment meant that participants entered a new hierarchically structured social field that functioned in familiar ways but with important differences. Most participants, however, reported that they embraced this change. Participants expressed that members of the healthcare team addressed them directly, they felt taken seriously, more in control and better informed about their own medical condition. Moving to an adult clinic was seen as a rite-of-passage, a move to becoming a young adult, which meant taking on more responsibility. In the following passage, David and Celia demonstrate their enthusiasm on how healthcare professionals interacted with them.

David: I think over here [at the adult clinic] you're more independent and, uh, I like that, as opposed to, like, the [paediatric team who] only speak[s] to your parents and tell them what's going on and that. I like to know beforehand what's, like, going on myself, so I like the way things are done and they tell you how it is, what you have to do to keep yourself healthy, and it's up to you to take care of yourself, basically...and that's, like, that's how I like things to go.

Celia: Yeah. I mean I'm 19 now, you know. I'm growing up, so it's just like, you know, I kind of want that responsibility of being me, like, you know, my own person, and just kind of grow. [...] Yeah, just being on your own, yeah.

Being positioned in a new social field, with new rules, was not without difficulties for some study participants. This required that recipients adopted a number of strategies in order to position themselves in the dominant healthcare culture in their new social field. In the following passage Celia describes how she was overwhelmed by healthcare professionals expectations of taking on more responsibilities in managing her medical care.

Celia: they had so many rules, like... you have to take on your own as a responsibility, you know, becoming an adult, basically, and not being a kid anymore and just... it was kind of a lot but as time, like, you know, progressed on, like, I'm like, "Okay, like, I get the hang of this," like, I'd have to call in and see when the appointments are if we don't know what's going on, like, they're not going to hunt you down, you have to have the responsibility of being an adult and knowing that your health always comes first, so it was kind of different because Sick Kids they'd, like, you know, they baby you, like... Like, they baby you and stuff like that and, like, you know, they'll take that extra step, but it's just like, you know, you're an adult now, you kind of have to do everything on your own.[...] like I've been saying you have to, like, be responsible of yourself.

What is being illuminated in the next few passages is that following the move from the paediatric hospital to the adult healthcare facility, recipients adopted a number of strategies that incorporated what is expected of them as responsible young adults, which are shaped in relation to the dominant discourse. Like Anna, all study participants incorporated their medical teams' culture. They ultimately reproduced these local assumptions and desires by demonstrating expected behaviours and dispositions of a responsible young transplant patient. Participants developed a feel-for-the-game, they acted in particular ways by reproducing local assumptions in a variety of ways that represented positive capital in this new social field.

Anna: Well, firstly I started, like, you know, getting more healthy, you know, uh, I go to the gym now, just like to keep up with, you know, my health and to be healthier too, and I call for my medications now. Like, for a refill, you know?

Anna: And, you know, I'm going to move in an apartment at college too, so I need to, like, get more responsible. Like, before I didn't... I helped my mom but not, like, that much, but now, like, I do a lot of things for her because, you know, she's my mom and [chuckles] I like to help her...at the same time it helps me too because, you know, I'll be doing that when I'm... when I'm at college, so... like, I clean around, mop the floors and stuff.

Participants described that following the transition to the adult clinic they were ready to make their own clinic appointments and could be trusted with taking their medication as prescribed. From a Bourdieusian perspective, this could be viewed as strategies that have been

constructed from a habitus that has internalized the goods at stake in the game. Managing one's own medical condition represents a positive cultural capital for the young adult transplant group.

Celia: But yeah, always make sure to take my medications. My mom's always on me for that. [...] She'll call my phone, call my phone, call my phone to make sure I take my medications, even though she knows I have an alarm on my phone. She just wants, you know, that satisfaction of her knowing that yes, okay, she took her medication. [...] I mean, it's kind of annoying, to be honest... [...] But yeah, I tell her all the time, like, I'm grateful for her calling me, even though at the time it doesn't seem like I'm grateful because, like, it just gets irritating because I know, like, I've been taking them for two years, but it's just like, you know, like I show her that, like, "Honestly, Mom, I appreciate your efforts in trying to push me and make sure you know that I take my medication ...

Anna: [taking my medication] ... it's nothing. I'm so used to it, I've been taking it since I was born, almost. [...] Yeah, I'm used to it. It's become a routine, really... because, like, I've taken it since I was, like, really young, so for me it's always been, like, normal. Like, I didn't start to take it when I was, like, ten, so it wasn't really like no medication then all of a sudden medication. So I always take them at the same time, like, I know now – well, I've always known – like, what time I have to take certain medications and... and stuff, and even when I go out I remember to bring them...and I never skip a medication.

Summary

Transition from a paediatric hospital to an adult healthcare facility was seen as a rite-of-passage for recipients. Participants embraced how healthcare professionals in the adult setting interacted with them; for example, recipients liked that members of their care team spoke to them directly about their medical conditions. Being in a new environment meant that participants had to incorporate a number of strategies, for example, adherence to medical routines, in order to be seen as responsible young adults. As demonstrated, not all participants were able to successfully do so. However, many recipients developed a feel-for-the-game, they acted in particular ways by reproducing local assumptions that were taken up as a form of cultural capital. There are further commonalities amongst the participants, depending on the context of the story s/he was relating to, all recipients demonstrated a lack of resistance to the dominant discourse of adhering to medical routines, which was expected of them in order to be “a good transplant patient”;

however, recipients struggled with relational position within other dominant fields. The concept of being a good patient, and recipients' prospect for resistance to the dominant discourse, will be further examined in the next chapter by highlighting the struggle between conflicting fields.

Chapter Summary

In this section, I have described the pivotal time extending from diagnosis with end-stage heart disease and subsequent life as transplant recipients to youth and young adulthood. After becoming ill, participants described common experiences of uncertainty, fear and a life put on hold. Becoming ill disrupted the previous flow of everyday activities, which cut across other social fields. All study participants missed school and completing various educational programs was seen as accumulation of important cultural capital. On the flip side, missing school limited opportunities for participants to establish social capital among peers. Frequent visits to a hierarchically structured paediatric clinic fostered practices of passivity, which aligned with overpowering positions of parents and providers with a dominant discourse of adherence that is managed by parents. Participants' restricted opportunities to interact with their healthcare team provided limited opportunities to develop different forms of capital. In the end, participants were prepared through a variety of teaching modalities for their pending move to the adult healthcare facility. This was mostly seen as positive, with some recipients reporting being overwhelmed by the provided teaching material. Transition to the adult health care system also changed the positioning of parents as their involvement in managing their children's care is de-emphasized as the youth become consumers. At that point the dominant discourse is still adherence, but there is greater emphasis on the youth to be the knowledgeable consumer instead of the parent being the knowledgeable guardian of the child's health. Transition was seen as a rite-of-passage and

participants' ingrained dispositions of being a docile patient were out of place and ultimately replaced by rationalizing practices.

PART TWO: FIELDS OF STRUGGLE: TRANSPLANT RECIPIENTS' RELATIONAL POSITIONS WITH OTHER DOMINANT FIELDS

Introduction

In this section I describe and interpret the social positioning of young adults who received a heart transplant during childhood and later transitioned to an adult healthcare facility. Drawing on the Bourdieusian conceptualization of hexis, or the embodiment of the social, I explore how study participants incorporate the dominant discourse of self-care and, how their practices function to reproduce or resist local assumptions within the dominant field of healthcare. During the interview many participants spoke about the effort to adhere to particular practices, which were emphasized by healthcare providers. Within these narratives, participants linked their behaviour to within-field struggle and ensuing symbolic violence, or having someone else's view imposed on them. Moreover, it was not only the conflicting interests within the healthcare field that were observable in this study, but recipients' struggles to reconcile the competing values of their social fields and the healthcare field. As recipients talked about not belonging to the transplant community, they aligned themselves with their healthy peers. The primary focus in this chapter is to demonstrate how participants struggle with relational positions within other dominant fields. Participants' behaviours, choices, values and styles in and across various fields are outlined. These strategies represent an expression of the habitus of participants and their struggle between the healthcare field and other competing social fields. Hence, in an effort to belong and not be labeled as different by their friends, participants expressed a reluctance to share their concerns and feelings about their illness with others and expressed feelings of loneliness. In the following section, I will further examine young transplant recipients' struggles within competing fields

Young adults align with one group while denying another, resisting the imposition of categories, rules and distancing from labels

Challenges of adhering to medical recommendations

Recipients’ effort to be “normal” led to a struggle of identity, practical routines and status of young adult transplant recipients.

This leads to an image where they put up a strong front and eventually cry alone.

II/a. It is not a big deal: It's just part of growing up

Introduction

Young adult transplant recipients position themselves (and are positioned) relationally within the hierarchy of the adult clinic. Participants described their discussions with healthcare professionals about how well they are managing as transplant recipients. They were aware of the concerns of the healthcare team about potential negative transplant outcomes and adherence to prescribed medication regimes and lifestyle modifications. Frequently, recipients conveyed a positive attitude, describing their effort and determination to adhere to clinicians' recommendations. I argue here that these claims represent the central symbolic capital of the transplant recipient that secures a relatively favourable position within the dominant discourse of illness self-management and responsibility.

Transplant recipients demonstrated embodied competencies that displayed maturity (attending diagnostic tests or clinics without a parent) and the commitment to work on their bodies (exercising, dieting, healthy lifestyle choices). Hence, they drew on culturally valued behaviours within the health service field to display symbolic capital. However, when some failed to adhere to biomedical cultural practices that were recommended by healthcare providers, their behaviour is inextricably linked to struggle within the field and symbolic violence.

Results

As highlighted in part one of the results chapter, actions and behaviours in the paediatric clinic were taken up by transplant recipients and reproduced in everyday routines outside the hospital. Study participants' dispositions suggested a passive and unassuming habitus. This was most strikingly observed in interviews where recipients described little interest in taking on more responsibility for their own care. Participants reported limited opportunities to develop social

capital (communication with healthcare professionals) as well as cultural capital (medical knowledge) due to parents being the guardians of their own health. In paediatric settings, participants indicated that they were less engaged in the practices of communication with health providers.

What is being illuminated is that as soon as study participants transferred to the adult transplant clinic, behaviours and assumptions within their new social field changed. As such, being a “good transplant patient” meant that recipients had to demonstrate maturity, which required them to alter their passive patient role and adhere to the dominant discourse of illness self-management by engaging more actively in their own care. Recipients acted in particular ways by reproducing local assumptions that were taken up as a form of cultural capital. Lucas was 22 years old and worked part-time at his brother’s photo studio. He had been followed in the adult transplant clinic for several years prior to his interview and he had this to say:

Lucas: I would just... like, advice I would give, basically, is just, uhm, probably to do what I did in the sense that go in to your doctors by yourself. Like, even if your parents are in the waiting room, just go in there by yourself, just to get a feel for it, I guess. Be more independent...not always have your mom and dad by your side, ...I know now what to ask and what to do, stuff like that.

Lucas had incorporated local assumptions of his current healthcare team and developed a feel-for-the-game, which Bourdieu calls doxa. This was demonstrated when he spoke about the importance of meeting his healthcare team without his parents. His own assumptive priorities had adapted to the new field, and he advocated particular behaviours that were concurrent with the expectations of being a “good patient”. However, he also viewed these behaviours as a product of personal insights accumulated over multiple encounters with health providers, not as practices that were constituted through gradual inculcation of the values of the health services field.

Like Lucas, most participants who had been followed in the adult transplant clinic talked about the importance of taking on more responsibility for their own care, suggesting that they had taken up and reproduced local assumptions of a more mature transplant patient. Ultimately, and over time this altered and conditioned their dispositions as transplant recipients. Some explained that this transformation also enabled a more relaxed conversation style between themselves and healthcare providers, denoting a more even distribution of power than in the paediatric setting.

Noah: It's not just them talking to me, it's just I find it's not, like, a strict doctor-to-patient conversation, it's more I guess a relaxed conversation, we're just talking. It's not... it's not them, "Oh, you have to do this," like, "Do this or else you're going to get sick," it's just, "How have you been? Is anything wrong?" Like, "What can we do?" and, "Nothing, I'm doing great." So it's, I guess, it's a more relaxed conversation, it's just us talking.

The following picture shows Noah during the interview and captures his relaxed conversation style during our meeting. His disposition captured in this picture might be very similar to his habitus during clinic visits. He demonstrated a very comfortable body posture and we were both very engaged during this interview, "it's just us talking".

The above passage was typical of the more egalitarian relationship that most recipients described achieving with their healthcare providers in the adult transplant clinic. This new practical communication skill was highly prized because it was thought to more favourably position recipients within doctor-patient relationships, suggesting accumulation of social capital.

As transplant recipients' adapted to adult health care, a new social field, they demonstrated a feel-for-the-game. Participants accumulated new forms of cultural capital as their medical routines became ingrained in their everyday practices. Stephan's story is similar to most participants in this study:

Stephan: ... so when people say to me, "Stephan, doesn't it take you long [to take your medication]?" Like, "Don't you hate taking your medicine?" I sit there, as I'm taking them, I say, "How long did that take me?" It took me not even a minute. So a minute in the morning, a minute at night.....it's nothing, right? You just have to remember. [...] Sometimes I forget and I take it a little bit later, but.....I still take it later in the morning, I just like smooth it.

Stephan commented that he has been taking medications since a very young age and this has allowed him to get accustomed to adhere to these strict medical regimes. These medical routines are ingrained in participants' everyday lives. During the interview, Stephan acted out his medication routine: "a minute in the morning, a minute at night...it's nothing, right?" He demonstrates additional cultural capital when he talked about how he modifies his medication schedule on days when he forgets to take his pills.

The following six pictures represent Stephan's medication routine during the interview. In following Heath's (2012) work expressive gestures are used during talk to reveal personal experience. Furthermore, gestures display, enact and (re)embody medical difficulties. What was represented as an insignificant medical act during the interview might potentially be a more

difficult action after all. As disclosed by Stephan “sometimes I forget and take it a bit later,... I still take it later in the morning, I just like smooth it”.

As the interviews progressed and study participants spoke about following strict medical recommendations, they also highlighted the challenges of adhering to these medical practices. Like Stephan in the previous segment, Lucas spoke about his routine of taking his medication and how he sometimes forgets to take his pills at night.

Lucas: [taking my medication] is not a problem, you know what I mean? “Problem” isn’t the right word, I guess, but...It’s a routine, I guess. Like, it’s not a problem in the morning when I... like, I’ll wake up, have breakfast, have my meds with my breakfast, but in the evening, I guess, if I’m out doing something, like, sometimes I’ll just forget, like, I’ve been doing it for thirteen years but still I think, “Oh, I still have to take my meds,” and stuff like that. It’s not a problem, I guess, but it’s something I have to live with, right.....so I just have to do it.

Similarly, Stephan expressed his feel-for-the-game by highlighting how he took care of his medical needs. What healthcare providers expected from him was to some extent second nature

to Stephan. Everyday practices were so ingrained and routine for him that he sometimes questioned if he had taken his medication at all.

Stephan: The medication is all fine. I've always been doing that since transplant pretty-well came out, so I've had to memorize my pills, my dosages, call in prescriptions, everything. [...] Yeah, and I have for some time now.....so it's just kind of second nature kind of thing. [...] it's just something I do in everyday life kind of thing, but the only pain is once in a while because it's a regular thing now, since I have to take them every day, once in a while I'll kind of think back, "Did I actually take them today?" and I realize I have, just because it's in my daily routine, but I just don't remember actually taking them.....just because it's so regular kind of thing.

What many participants did not mention was that missing immunosuppressive medication can potentially negatively affect the transplanted heart. Graft rejection is a significant concern in young adults and some participants did not closely monitor their medication regime. Many study participants glossed over the difficulties of adhering to strict medical protocols and being “a good patient”. At the same time, some recipients reported that they smoked, while others also admitted to using alcohol or drugs. For one study participant keeping up her medical regime became very difficult. Olivia was just recently transferred to the adult transplant clinic. During the interview she spoke about her difficult family situation, her hectic life, and her depression, diagnosed several years ago. Olivia responded to pressures from various fields by stopping her medication.

Olivia: I was being really stupid and I stopped taking my pills. And I just, like... Uh, I just didn't care anymore, and I didn't think that I was ever going to get rejection, because I was, like, "Oh, well, it's not going to happen because if I was going to get rejection it would have, like, happened already," and stuff, not six years later. I just honestly didn't care, like... I was just... yeah. I was really depressed, didn't, like, I didn't talk to anybody about it or anything. I was just I was just in a really bad state. [...] Yeah, a lot of family issues, and living issues, and just everything was really hectic.

After Olivia stopped taking her medication over a period of several months she became very sick. She stated that she was not able to talk to anyone about her worries. She was initially seen at a hospital closer to her home and healthcare professionals did not take her concerns

seriously. She was labelled as someone who was abusing pain medication. Olivia was admitted to the local hospital for several days and was sent home without any close follow up.

Olivia: I was admitted [to the local hospital] for a week and a half and then they just sent me home. And then I was home for a day, and then I guess [my boyfriend] tried to wake me up and, like, he couldn't wake me up or anything because I was breathing really weird, and then, like, finally I opened my eyes but, like, I looked really scared, he said, and like he was talking to me but I couldn't, like... he said that I looked like I was trying to talk but, like, I couldn't talk to him or anything, and then eventually, like, I said, "I can't breathe," so then he called 911 and then they brought me back to the hospital and then I was there and they told me that I was being a baby and just trying to get pain medicine and stuff like that, and then they gave me, like... they said that I had pneumonia, and then they gave me, like, a Ventolin treatment and sent me home.

Olivia's experience represented one of the more severe cases in this study. Her story was included in this section because it crystallized the multifaceted social and medical issues young transplant recipients face. As teenagers become young adults, many struggle with issues of independence. Eventually Olivia presented to the adult transplant clinic at which point her physical condition had deteriorated severely and she was diagnosed with severe acute graft rejection and shock. She was admitted to the inpatient unit in order to receive treatment for her graft failure. As Olivia reflected on her recent admission to the hospital, she had this to say:

Olivia: I feel like something like this did needed to happen to me just so I would smarten up, because I know if nothing like this had of happened I'd still be, like, smoking cigarettes and doing drugs and drinking and, like, just [chuckling:] being really stupid. So I feel like I've matured a lot from this and, like, something like this did need... maybe not so traumatic or, like, as bad as it got but, I mean, things happen for a reason, so... and I'm still here, so that's all that counts, really. I'm never going to miss my pills again. Like, I definitely learned from this. It made me a better person, I feel like.

Olivia talked about the fact that she "matured a lot", which perhaps was brought up during the interview to mitigate the appearance of being immature or senseless based on recent mishandling of her health. She attempted to show symbolically valued capital - such as medical knowledge - by stressing the importance of adhering to strict medical regimes and the fact that medications

have to be taken regularly. Olivia, like many other young transplant recipients, reported that no one understood what she was going through. Not being able to talk to someone about difficult events leaves recipients isolated and potentially unable to resolve complex challenges in multiple fields of endeavour. As demonstrated in this case, when severe medical situations arise, young adults may have trouble acting according to adult rationalities. Medical emergencies are outside recipients' everyday routines, which go beyond healthy living, dieting and taking on more responsibility for one's own care. Not having an open, inclusive and clear dialogue between young adults, their families and healthcare providers creates barriers that contribute to recipients' exclusion across various fields.

As highlighted throughout this section, study participants demonstrated embodied competencies that displayed maturity, as they took on more responsibility for their medical care. When some recipients reflected on what was important for them and how they wanted to live their life, they made statements like these:

Ingrid: So, I mean, how do I feel? Uhm, I feel like it sucks. [chuckles] I feel like it sucks, I feel like such is life.....uhm, [chuckling:] life sucks sometimes.....but I feel like I'd love to be healthy and, uhm, you know, sometimes I, you know, I feel like... you know? But on the other hand, you know, it's hard to look at, like, the glass full when, uhm, when I see all my friends... like, I'd have to excuse myself to go to the washroom to take my medications and, uhm, they don't have to. You know, I have to carry them around, that if I don't have them on me, uhm, if I don't have them on me then, uhm, I have to go home. I can't just sleep over at a friend's house without having everything with me. Uhm, it's like little things that I kind of, like, I'm jealous about, it's something that I'll never... I feel like I'll never have. And it's not a big... it's not a big deal, but maybe because I'm... I hang out with... like, I don't hang out with people who have any medical issues. So probably if I did then I would feel lucky, but... uhm, and I do, I feel incredibly fortunate. I mean, like... and so super-thankful...and, uhm – super-thankful – and, uhm, but I don't know, like, there's parts of me where I just like, you know, it would be a lot easier. Like, you know, I sometimes think, "What could I have done if I didn't spend so many years in hospital? What could I have?"

Olivia: ...I got a second chance at life, like, quite a few times now, so I can try and, like... I'm never going to have a normal life, I've accepted that just 'cause I can't really... pretty-much like I can do sports and I can, like, go to school and, like, pretty-much stuff

like that, but, like, I do have to always, like, take medication for the rest of my life, I do have to come and do treatments and different tests and stuff, like, I'm always going to have to do that. Like, I mean, it's always in the back of my head that I'm not ever going to have normal life, but I mean it's like a lot better quality of life than I would have had if I didn't have a transplant – I wouldn't be here – so I kind of accepted it. There's not really anything I can do about it, so I move on from it, I don't dwell on it.

Although Ingrid's and Olivia's accounts are very distinct, they equally acknowledged that due to their medical condition they will never be able to live a life similar to their peers. Both stated that they are very thankful and lucky to have been given a second chance at life. However, their narratives highlight that the transplanted heart does not come without burden. All recipients reported on the difficult task of adhering to strict medical routines and lifestyle modifications. And since participants described that they preferred to spend time with healthy peers, they take up and reproduce local assumptions of their peers' social field, which is very distinct to the dominant healthcare discourse. Functional ability and social connectedness with friends were of importance for most participants; however, it is the need to adhere to strict medical regimes that creates a disruption in their everyday existence.

I/b. Body-work

Study participants demonstrated a particular doxa, or a feel-for-the-game, as they spoke about their commitment to work on the body, a form of symbolic capital, which ensured them a favourable position within the dominant discourse of self-management. Stephan and Peter provided the following comments:

Stephan: I've tried to take... like, I'm taking care of myself, I exercise a lot. Like, I made these promises to myself that once I was able to I would exercise, I lost a lot of weight, I... I don't drink. I drink socially... I don't smoke, I don't do drugs – except the drugs they give me – And that's it. I just... I take care of myself.

Peter: Well, firstly I started, like, you know, getting more healthy, you know, uh, I go to the gym now, just like to keep up with, you know, keep my health and to be healthier too.

During the interview, Stephan pulled a picture from his wallet that showed him about 50 pounds heavier. The difference between his former and current physiques captured and illustrated his commitment to work on his body, and in so doing, clearly displayed a valued capital. It is conceivable that Stephan thought of me as a member of the healthcare team, and therefore showing a picture to vouch for his bodily transformation supports his claim to a favourable position within the healthcare field. Although most participants pointedly explained that drinking alcohol and engaging in illicit drug use was not something that they engaged in, many of them stated that they drank socially. For many study participants “social” drinking was offered as an acceptable or benign level of alcohol use in comparison to heavier drinking or drug use. It is apparent from the interviews that most participants normalized “social drinking” of alcohol.

For a few male study participants the dominant discourse of a healthy lifestyle meant that they continued to push their physical activities in order to be competitive during sporting events. As demonstrated in the previous chapter participants talked about how difficult life was when they fell ill. It is a profound statement when a person who had received a heart transplant demonstrates their commitment to health by exhibiting a very high fitness level. Lucas and Peter are both very active transplant recipients and they had this to say:

Lucas: I went to Transplant Olympics ...Uhm, while I was there I played tennis and a lot of the track events. [...] I haven't been to one [training] recently, just 'cause of school, but I do hope to go to another Transplant Olympics. [...] I'll go to the gym but I don't train specific for this. [...] It was... it was fun, probably one of the funnest experiences I've had.

Peter: ...since the heart transplant I've been able to compete competitively in anything. [...] Oh, yeah. Yeah-yeah. I played rep soccer for a long while after my transplant, probably from when I was 8 until probably 15. I played competitive soccer, and then I only quit because of school, I wanted to focus more on school instead of sports. But I don't... really I can keep up with my friends in anything, anything physical I mean.

Physical fitness is a form of functional ability that encompasses cultural capital, particularly for young men. Having received a heart transplant and competing at sporting events situates recipients within the most favourable position within the discourse of illness self-management.

For female study participants a commitment to work on the body also included adhering to a strict healthy lifestyle regime, which frequently was expressed in very concrete ways. Ingrid followed a particular diet and she had this to say:

Ingrid: ...I started... I started this health kick...which is called the calorie-reduced diet. [...] ...and the whole concept is eating so every calorie that you do, that you eat, uhm, your body puts out these free radicals – like the science is not my thing – but so every calorie that you put into your body has to be ... packed of nutrients. So, for example, I eat raspberries because calorie for calorie they have the most fiber out of any food, or I eat sardines because they have a lot of protein and they have calcium.....or I eat Greek yogurt because it has a lot of protein, not that many calories. Or, uhm, like I don't eat sweets and I don't eat bread, I eat like fibre cereal. So I mean it's not something too crazy, and it's not like my calories are, like, 500 calories, it's more like a 1500-calorie diet.....where I eat a lot of, like, kale and, like...The good stuff, right. ... but really, like, I, you know, I measure and make sure that... but I mean you can't do that every day, so but I do that maybe like three times a week. So why do I do that? Because I want to be healthy...

Ingrid stated that she adhered to her strict diet approximately three times a week. However, she also mentioned that on her non-diet days she liked to treat herself to very large high calorie

coffee blends. As captured in the picture above, she brought one of her favourite drinks to our meeting that she sipped on during the interview. She explained that this is a way of treating herself when otherwise she adheres to her strict diet. In general, few female study participants spoke about the importance of being physically fit, and did not describe competitive sports as an avenue to fitness. They did, however, often use dieting as means to live a healthy life that represents culturally valued behaviour in their particular social field. Additionally, female study participants included dieting, a form of body-work, in order to comply with socially acceptable norms of what a female body should look like.

Summary

During the interview many participants spoke about the effort to adhere to particular practices, which were emphasized by healthcare providers. Within these narratives, participants linked their behaviour to within-field struggle and ensuing symbolic violence. Moreover, it is not only the conflicting interests within the healthcare field that was observable in this study, but recipients' struggles to reconcile the competing values of their social fields and the healthcare field. As recipients talked about not belonging to the transplant community, they aligned themselves with their healthy peers. In her statement above, Ingrid talked about her medical responsibilities and the fact that she is not spending any time with individuals who have any medical issues, which highlights her challenges in negotiating a position within each field of endeavor. For these young adults being sick and taking medication conflicted with their determination to appear to follow the healthy carefree life. Young transplant recipients' struggles within competing fields will be further explored in the next section.

II. The new “normal”

Introduction

Following Bourdieu, skill at cultural practices, or the ability to function smoothly within a particular field, is a classifying principle that facilitates accumulation of valued capital. In the clinic, accumulation of symbolic capital such as physical fitness or adherence to medication regimens enabled recipients to represent themselves positively and improve their positioning within a field. However there were indications in the interviews that within the other social fields occupied by recipients and their peers, value was placed on physically active and able practices as a normative way of being. Youth who were ill were apparently afforded limited opportunities to accumulate capital such as friendship networks and even educational credits. Interestingly, most participants described themselves living “normal” lives. They constructed living with their illness as living life as “normal”, which was a strategy for negotiating positive positions for themselves, particularly given the push in the healthcare field of personal responsibility and self-management. By maintaining health, study participants were able to uphold physical ability which allowed them to reconcile their existence as a transplant recipient by living a life similar to their peers.

Results

Many study participants spoke positively about their appearance and functional ability as young adults within their social field. Functional ability, in the form of physical capability and maintaining social connectedness with their friends, represented cultural practices that were deemed important within their peer field. In their descriptions of peer social life, participants emphasized what they were able to do and how similar their physical appearance was to that of their friends in constructing themselves as “normal”. Within their respective fields, functional

ability enabled recipients to accumulate various forms of capital. What was deemed important in recipients peer fields was the ability to form relationships (social capital), as well as the capacity of being able to keep up with friends, a form of functional ability (cultural capital). Most study participants were able to accumulate at least some of these forms of capital and therefore did not think of themselves as transplant patients. Ingrid spoke about the importance of engaging in activities that allowed her to connect with friends in order to have more common interests. She had this to say:

Ingrid: ...but I think there's more important things for me to do. I think it's better for me to kind of go towards the general population side of things and be kind of the same with my peers than it is for me to sit and to plan my things around my medications, to plan... uhm, I think it's more important for me to read the books I'm going to talk to my friends about, or, uh watch the TV shows [laughing:] that I like, right, that I can talk to my friends about, than it is for me to be more involved in my... my care. I don't know how much there is for me to... to know right now because I'm quite healthy right now...

Ingrid's story depicts a focus on engaging in activities that strengthened friendships and reinforced belonging within peer networks. She prioritized reading the same books, and watching the same shows as her friends over further involvement in her health. In this respect, participants emphasized the value of peer relationships. In remarking that study participants emphasized or prioritized relationships within their peer fields, I do not suggest that recipients do not contemplate their relational positions within other dominant fields, like the healthcare field. However, activities that promoted friendships and fostered belonging within peer networks was a common topic and none of the participants reflected on potential negative consequences that might result from such priorities.

Anna explained that she belonged with healthy, "normal" people. At times she felt frustrated and disadvantaged when she compared her life to those of her friends. Being active and able was culturally valued within her peer network and Anna was working hard to live a

“normal” life as a transplant recipient. To be perceived as a typical university student was very important for Anna as she spoke about her ongoing fight to be “normal”.

Anna: ...I don't want it [my heart transplant] to define me, I feel like, uhm, I don't belong with the sick... sick people, I belong with normal, healthy people, so, uhm, I feel... but on the other hand, you know, there's some... some stuff that go through my head, so I feel... sometimes I feel like... you know, I'm a really optimistic person, but sometimes, especially since I hang out with the ordinary people, I feel... I feel jealous about that. You know, I feel... I feel like it sucks. [...] I feel like so many kids are healthy, so many kids they don't have any medical issues and they've never had... they've always been normal, always, and it's almost like I'm fighting to be normal.

These kinds of statements were relatively typical of young adult transplant recipients in this study. Most participants thought of themselves as optimistic individuals, but struggled to position themselves as “normal”. Nevertheless, nearly all participants thought of themselves as “normal”. The term “normal” was used when participants compared their habitus to other healthy peers embodied dispositions. The interaction between healthy peers’ hexis, or embodied dispositions, and participants deliberate choice (agency) revealed particular strategies – participants thought of themselves as “normal” – which represented a form of learned understanding of the world. Rather than attempting to discover what “normal” meant for each person, I considered it more instructive to examine the effects of claiming “normal” as a personal attribute. The act of claiming “normal” could potentially serve to reconfigure one’s assigned place of marginality in a social hierarchy. “Normal” is a neutral characteristic, claimed by all kinds of persons with all kinds of medical conditions and is not exclusively associated with marginalized “others”. Without conscious intent or manipulation, participants resisted exclusionary forces by claiming a neutral personal attribute as they interact with peers within their social field. This positioned them as “players in the game” and contributed to building and sustaining a positive public and self-image.

The following passage captures participants' efforts to improve, or resist being categorized as sick or unhealthy within their social field. The focus is on the centrality to social positioning of shared behaviours, choices, values and styles within a social field. Noah's statement was pervasive as he spoke about his transplant being in the background and he embraced the habitus of a "normal" university student that focused on his studies and having fun.

Noah: I feel... I don't have any complaints. ...I'm living a normal second-year university life. I ... unless I'm taking my meds – which is only twice a day – I really... I don't think that I've had a transplant, really, or look at my scar. I really... it's almost like a background thing, now. [...] My friends are, I guess, normal people. We all... we all study science, the people that we live with, or that I live with, so I guess we're all nerds in the fact that we love... we love just talking about science if it comes up. Uh, they're normal second-year university students, we focus – or we try to focus – on our schooling, but we'll go out, we'll have fun, too. I mean, yeah, I mean I can't really explain it much in the fact that we're just normal university students.

The following picture shows Noah and demonstrates his self-representation of a "normal second-year university student". The picture visualizes certain local meanings of Noah's notion of "normal".

His hairstyle, moderate facial hair and trendy t-shirt represented a particular "hipster look"

currently trendy with young people. In comparison in the photo below, Peter also thought of himself as a “normal” young person by wearing a baseball cap, baggy clothing and a hoody. His way of dressing was very distinct from Noah’s but both young men referred to themselves as “normal”. Style is a form of self-representation and in keeping with Bourdieu are indicators of class because trends in consumption seemingly correlate with an individual’s fit in society. Hence, both individuals understanding of “normal” was influenced by their particular fit within their social field. The social is taken up by these young adults and reproduced in the form of hexa, or the embodiment of habitus, here in the form of dress code and style. Both images are illustrations of these young males’ social fields and their understanding of “normal”.

Being “normal” was also important for Stephan who worked part time at his brother’s photo studio. He resisted social behaviours where people felt sorry for him and instead thought of his heart transplant as normative way of being. He provided the following comment:

Stephan: I hate when people feel sorry for me, because I don’t feel sorry for me, I tell them. I say it’s just... just whatever, I’m normal. It’s normal. I needed a heart transplant so it’s basically me needing a new engine in my car. If I didn’t have it I’d... I’d be done.....so because I had it, it’s just normal. [...] And I’m just going out, having fun.

Stephan used the analogy of a machine model to highlight that organ transplant can be thought of in similar ways as a car needing a new engine. Thus, an exchange of spare parts, in his view, becomes a trivial and routine process. Additionally, Stephan suffered from a stroke at a very young age that left his right arm paralyzed. He has adopted a habit of moving his left arm with his paralyzed limb, so that at first sight one does not notice a physical disability. He moved his arm effortlessly and has incorporated this into a “normal” way of being. The segment of pictures below captured his routine:

He positioned himself as a “player in the game” who was not in any way different from his peers. He described sustaining a positive public and self-image and thus resisted being identified with what a sick person might look, feel or act like. In particular he described avoiding the pity of others, which positioned him unfavourably in relation to others. Instead Stephan described his efforts to frame his surgery in terms that restored the identity of a young adult who was outgoing and having fun.

A normative way of being in the world for study participants meant that they had functional abilities similar to their peers. The majority of study participants provided statements similar to Noah's; highlighting that young transplant recipients have limited restrictions and behave similar to their peers.

*Noah: Uh, I guess just, uh, hang out. Uh, we'll go... go downtown, go for drinks. I mean, there's really... whatever my friends will do there's no restriction on what I can do. [...]
Yeah. I'm... I'm very happy with my life, considering what I've been through.*

David commented that being able to spend time with his friends meant spending time downtown and visiting clubs.

*David: I'll go downtown to, like, different venues, uh, and places, like my friends do... ..performances and shows and stuff, so I go and check that out, like. I don't have any boundaries, really, when it comes to stuff like that, like, I'll go out and do whatever. [...]
Well, we go downtown to, like, different clubs and stuff like that.....and just hang out. Yeah, I can pretty-much do anything. No real restrictions ...*

All recipients emphasized positive aspects of their function within their social fields. In the above interview excerpts, participants conveyed how they were very happy with their lives, had no physical restrictions and enjoyed being social. These dispositions and abilities are normative ways of being, cultured practices that have been shaped by the world around them.

Nevertheless, what was considered a normative way of being was dependent on participants' geographical location. The majority of recipients lived in urban environments or larger suburban communities. This meant that friends lived within the immediate proximity and time together was spent at various events or social activities their city/community had to offer. A few study participants lived in very remote areas, and for these individuals it was difficult to connect with peers. The following statement highlights Gail's insights into her own feelings, as she openly discussed her loneliness.

Gail: Oh, she [mother] says she thinks I'm depressed but I'm going to say no because I have been depressed, I know the difference between [sighs] depressed and loneliness. So I'd say I'm kind of lonely most times, but I'm not depressed [...] Well, I mean if you're depressed, usually you don't want to do anything at all, you don't do the things you even like to do. You, I don't know, kind of hide yourself [chuckling:] away from everyone. And loneliness is just kind of wanting friends who you can talk to. You still do the things you like to do...you don't always [chuckling:] hide yourself.[...] and I guess because I usually spend most times in my room, [my mother thinks I am depressed] but that's where [chuckling:] my videogames and computer are

For some, family and siblings provided the main contacts outside of school. During the interview, Gail talked about her limited ability to meet other people around her age due to her remote living arrangements. After school she frequently spent her time alone in her room and her computer was her only connection to other individuals. During the interview she mentioned that her parents interpreted her behaviour as a sign of depression, but she assured them that she just felt lonely. As outlined in this chapter maintaining social connectedness with friends represented cultural practices that were deemed important within participants' social fields. Gail's remote geographical position provided limited opportunities to connect with peers and hindered her to accumulate social capital. This might ultimately put her at a disadvantaged position when coping with her illness.

Ingrid commented that when she is not in school she does like to go out several times a week. Meeting new people and being social is a way of being that is new and exciting for her, an experience that has definitely changed since high school. As outlined in the previous chapter, Ingrid explained that she was always seen as an outsider when growing up because her body looked different and she frequently missed class because of her illness. At one point she even required a walker due to a spinal injury, further highlighting to her classmates that she was not like them. As she has grown up her appearance has changed. During the interview she had this to say:

Ingrid: ... now that I'm on vacation and I'm a resisting single I... I go out.....uhm, like maybe, like, four or five nights a week... I go to [the pub on campus]. It is, uhm... they have the best wings. I, uhm... they have, this, hammer sauce which is like a blend of, like, different sauces, and so they smother it in the sauce. And they have \$10 pitchers as well. And it's where all the engineers go, and so it's my favourite place to go because I like hanging out with the engineers.....uhm, but I also feel like... like, I acknowledge that I'm a pretty girl but I have these really intense glasses, like, my vision's horrible, and so when I go to, I don't know, places like the [local pub]. – which is like the frat, uh, kind of pub ...then I don't get hit on as much as when I go... when I go to [the pub on campus]., and when the guys learn I play chess it's like, I don't know, it's like... it's like a moth to a flame, like, it's... so, I mean, like I like [a pub on campus]....

Ingrid acknowledged being pretty and enjoyed being social at the local university pub. She demonstrated a sense of pride and accomplishment in the way she presented herself. The following picture captured her self-representation as a young attractive woman. Ingrid was wearing makeup and nail polish and dressed in a fashion forward way for the interview.

Ingrid's statements suggested an underlying assumptive belief that being smart, pretty and having an interest in playing chess enabled her to socialize with men. Her statement about

wearing very intense glasses, in her opinion, depicted her as an intellectual woman and by doing so she attracted particular type of men. Ingrid portrayed in the interview that for her, living with a transplant is a normative way of being. I am not suggesting that this was a calculated decision, but rather a reflection of her situated habitus. Her peers reinforced her habitus by showing interest in her. The suggestion here is that appearance and flirting with the opposite sex is important for young adults.

Participants' resistance to be labeled in a particular sick role within their social fields generated the "new normal" by constructing themselves in a positive public and self-image. Being functionally able allowed transplant recipients to accumulate various forms of capital. Participants were able to construct themselves positively within their social field; however, their bodies were marked by scars from previous surgeries. Celia spoke about an event where she was on the bus wearing a low cut top and noticed other girls making negative remarks about her scar, she had this to say:

Celia: [Interviewer: Do the scars bother you?] Yeah, a lot. I don't like them at all. I remember one time I wore a low top on the bus and then this girl was, like, these girls were like, "Look at her scar." I just felt like, you know, like I felt less as a person because it was just like, "You don't know, like, where my scar came from, so you can't really speak on it," like, you know, but people are so ignorant, like, they don't care. [...] I really, really don't like my chest scar. I mean, I even have scars on my stomach here because I had a Berlin heart. Yeah, so I have, like, scars everywhere, so I'm kind of self-conscious about it. Like, I always feel like, you know, like I have to... like, I don't have any low tops, I don't wear low tops at all, whereas like, you know, I have to wear something high up... Like, I can't wear... like, I don't feel like I can wear low tops. And it's like when I want to go shopping it's kind of frustrating because just like, you know, all these cute tops and cute dresses and, like, I can't wear that, like, you know, without somebody pressuring me about what happened to my chest.

The picture below captured Celia's style, portraying her need to always cover her chest.

Her experience on the bus made her very conscientious about her surgical scars. Such an experience made her change the way she dressed in general, making sure her scar is always covered and not visible to others. Hence, she adopted a more conservative dress code, which also downplayed potential feminine capital. In comparison, Ingrid in the previous image presented a very fashion forward appearance of a pretty girl while wearing a concealing scarf.

Healthy young bodies are deemed culturally valued and participants reproduced these social values. These values impacted recipients abilities in self-assessment of their worth as potential intimate partners. Most female study participants commented negatively about their scars. They described what their scars looked like, how they felt very self conscious about it, and how they dressed in order to conceal the marks on their bodies. Participant's spoke about negative public experiences that ultimately influenced how they think about their bodies. These women thought of themselves as potentially not being able to be loved because of their prominent surgical scars. In the following passage, Olivia discussed how she felt about her scars and how these scars might impact her life.

Olivia: Uhm, I don't know, I kind of just... it sucked, just 'cause, like, I was, like, worried about all my scars and stuff, and I'm like, "Oh, nobody's ever going to like me now," and stuff like that. [...] Well, and I was also on, like, this life support machine called the Berlin heart pump...so, like, there's like four holes in my stomach.....so, like, I was like, "Oh, I've never going to be able to wear a bikini or anything like that," so.....it kind of made me feel bad about my body, [...] I'm more worried about what other people think of them. So I'm used to them now, but at first it was really hard.

Some participants reported giving vague answers when others asked them specifically about their scars:

Gail: [Interviewer: Do you think about your incision?] Not really. It doesn't bug me. Sometimes people ask, I just say, "Oh, I had surgery." I don't [chuckling:] go into details. And [sighs] yeah, I don't really care about the scar.

As observable in the picture above, Gail wore a low cut top during the interview process, with her scar clearly visible. She talked about the fact that she “[doesn’t] really care about the scar”; however, she frequently lifted her arms up to her chin during the interview that appeared as an act of covering her scar, as demonstrated in the picture below. She frequently chuckled and

sighed when she talked about her large scar on her chest. In keeping with Heath's understanding of analyzing visual representations, these expressive gestures might demonstrate underlying emotional difficulties. Both are a particular bodily conduct that transforms the presence of a scar into a form of suffering.

Alternatively, other participants avoided questions about their scars altogether and further downplayed the event, using humour to deflect discussion.

Celia: ...you know we all have chest scars, right, but, uhm, she was telling me one time, like, this guy kept looking at her chest scar and then he's like... he just kept looking at her chest scar and she's like, "What?" and then he was like... he was like, "Oh, my god, what happened?" and she's like, "Uhm, shark attack." Like, it was funny, you know? Like, she's like they're so nosy, like, they just want to know, like, everything, you know? It was so funny the way she said it. I was, like, I was dying, it was so funny. She's a cool girl.

Celia and her friend dealt with the stares of others by reclaiming power within the encounter, unbalancing the stares with humour. The following quotes by Anne and Gail suggest that they are comfortable talking about their scars to other people. At the same time during the interview, Celia wore a lower cut top and did not hide her scar. Being stared at and asked about the scar can perhaps become an expected response, written into the habitus as part of the everyday world. This does not suggest the situation does not have a marginalizing effect. Celia's reaction can be seen as a periodic resistance to the disabling stares of others, a resistance that helped her to (re)claim power and position. In contrast, Anna was one of the few female study participants that reported that she did not hide her scars and she felt comfortable talking to people about her transplant.

Anna: No, I'm used to it [my scar]. Like, I don't try to hide it or anything, I just... that's who I am I'm not going to try to hide it, I mean, it doesn't do anything to hide it, so... plus people ask, well, I just tell them, I just... like, it doesn't bother me to tell them [...] Like, some will just, like, leave it alone, but some will be, [...] some people that I never met, like, they'll be like, "Oh, what's that?" like, "Why do you have that?" I'll explain to them, "Like, well, I had heart transplants, and..." Yeah.

As visible in the pictures above, Anna wore a low cut top during the interview process. However, Anna, like Gail, often positioned her arm under her chin in order to cover her chest. She also frequently placed her hair so it covered her scar. The focus of my analysis here is not so much the context of the photograph, but how the context provided meaning to Anna's statement. She indicated that she does not try to hide her scar, but the pictures captured that the hiding of the scar might demonstrate emotional difficulty. However, hiding the scar may go beyond emotional or psychological issues. It might be an accomplishment to both wear the revealing clothes that show off feminine capital within particular peer contexts and simultaneously conceal the scar that denotes stigmatizing health issues. In this way, young women perform a balancing act of both revealing and concealing, ultimately having to own up to their scars but also demonstrating feminine capital.

Summary

Young transplant recipients reproduced culturally valued assumptions about what male or female bodies are supposed to look like. All male study participants reported that their scars did not bother them and they rarely thought about their incisions. It is conceivable that such comments reflected the prevailing assumption that scars on a male body might be interpreted as masculine, in keeping with being tough. Additionally, young men don't usually wear necklines

low enough to reveal scars. Alternatively, female study participants thought carefully how to best conceal any scars and to represent their body in a particular way. All participants were concerned with the relationship between body, image, and how this might affect potential peer relations. In other words, appearance of a person's body is pivotal to social acceptability. This seems to reflect a popular assumption that the body is a reflection of the self and the person's inner character or personality will shine through the outer appearance. Ingrid's relief at her attractiveness to young men suggested that young women recipients feared their scars might be viewed as flaws and could disqualify them as lovable. On the other hand, recipients assumed that concealing scars and representing an enhanced appearance presented a body that was more congruent with their "true" selves. This concealment was necessary to transform the self by constructing a new "normal" through the representation of their body in a particular way.

III. Changing biographies in midst of a healthy peer field

Introduction

The majority of participants expressed a reluctance to share their transplant experience with others. Recipients explained that nobody understood what it was like for them to live with a transplanted heart, including their ongoing suffering. The risk of being deemed different, not being a "normal" young person, informs recipients' logic of practice. They position themselves relationally within their social field of young healthy adults. This illustrates the enduring effect of the habitus and the accumulation of symbolic capital. Participants developed a feel for the game, a (mis)recognition of what was important, which led them to inhabit their bodies in particular ways. Recipient's taken-for-granted views suggest cultural ideologies of illness behaviour. Given the cultural order, it is understandable that these young adults put on a "brave face" and cry alone. Following Bourdieu, this is an example of how structure (cultural rules) and

agency (choice) blend. It is important to note that it is transplant recipients who run the risk of negative self-labeling, which allows symbolic violence to operate, rather than others imposing negative labels.

Results

Within their own social field, young adult transplant recipients positioned themselves as “normal”, healthy and capable individuals. As established in the previous section, recipients struggled and fought to be more like their peers. In an effort to not be seen as different by their peers and to belong to a desired social field, participants reproduced local assumptions of what is culturally valued among *healthy* young adults. They behaved in particular ways – not taking their medication in front of their friends, drinking socially, going out to pubs – a (mis)recognition of what healthcare professionals deemed important. In embodying the capital and practicing valued activities of their peers, the youth contradicted the values of the health services field. Participants ultimately began to hide or negate particular facets of existence as a transplant recipient. Inevitably, transplantation is associated with physical and emotional challenges, as most participants acknowledged during the interviews. Since participants elected to represent their bodies and practices in a certain socially acceptable ways, they described reluctance to share their innermost concerns and feelings with others. This logic of practice has also been cultivated during their formative years as young transplant recipients, because some were frequently bullied or marginalized based on appearance and their medical condition. Furthermore, although habitus is not static, participants’ dispositions highlighted the enduring effects of habitus.

It was common for study participants to claim that nobody understands what it means to live with a heart transplant. Noah’s and Ingrid’s tone of voice dropped and became quieter

during the section of the interview where they expressed their feelings about not being understood. They elaborated:

Noah: I don't really talk to anyone, it's pretty-well I've always kept it to myself kind of thing, where... but the only person or only people that I would say that would know kind of what I'd been going through is other people that have also had transplant and such...

Ingrid: I don't know if there's ... I don't know if there's some...like, I guess everyone's unique...and maybe I'm being dramatic, here, but I don't know, I don't know anyone...anyone can understand.

A number of recipients reported that no one understood them. That only someone who had a heart transplant could know what it is like to live with a transplanted heart. Hence, only other transplant recipients were truly able to understand the experiences and challenges they were going through. Participants expressed that living through heart transplantation cannot be compared to any other medical condition. They reported it was very emotional, distressing, and physically demanding. It also became apparent during the interviews that study participants, who were all in their early twenties, only wanted to connect with a transplant recipient who was similar to their own age. Participants talked about meeting older transplant recipients during clinic visits, but they felt that they were not like them. In our clinic the typical heart transplant recipient is on average fifty years old and 70% of them are male. Ken and Celia talked about their experience of knowing few people who are like them.

Ken: A little, like, a little different, because I'm the only one that I know of that has a heart transplant. There's only a few, a handful that actual have them. [...] I guess around my age or so. I'll say I don't know anybody else who has a heart transplant.

Celia: I'd just rather kind of keep to myself. [...] because I just feel like, you know, if I've been through that, like, by myself, I just feel like I can go through anything by myself, then so be the case, I've gone through a lot, and it's just like that was one of my major things that I've gone through so it's just, like, you know, I can do a lot on my own.

All recipients felt that their experience was unique. It was common for participants to express feelings of loneliness and having no one to talk to who has been through a similar experience. Since some participants declined to make friends with other transplant recipients - because they wanted to be with normal people, or they felt that they had very little in common with other recipients - they are imposing symbolic violence on themselves. Following Bourdieu's understanding of symbolic violence - which means imposition of a dominant view on others - study participants, would by definition reject youth like themselves as friends

Summary

Transplant recipients are caught in a contradictory position wherein they escaped death through the performance of a very radical surgical procedure requiring ongoing therapeutic interventions, yet they must simultaneously fight to be “normal” in order to belong to their peer social field composed of healthy young adults. Transplant recipients require ongoing medical management and are cared for in hospitals and outpatient clinics. The logic of practice within the healthcare field requires recipients to accumulate medical knowledge and be an active participant in managing their care as they adhere to strict medical regimes. As outlined in this section, recipients reported being ready to take on more responsibility in managing their own care, but still struggle with everyday routines, like taking their meds, when they are out with their friends. What is at stake here is medical knowledge, a form of cultural capital within this particular field. In contrast, recipients position themselves relationally within their social fields of healthy young adults. The question of “who am I as a person?” is being addressed by reassembling themselves as “normal”. Participants developed a feel for the game, a (mis)recognition of what is important, which leads them to be in their body in a particular way. As expressed by Noah during the interview: “I am a normal university student”, recipients are motivated by a need to maintain a

positive “normal” identity. Recipient’s taken-for-granted views highlight cultural ideologies of illness behaviour. Given the cultural order, it is understandable that these young adults put on a “brave face” and cry alone.

Chapter Summary

As presented in results chapter 1, when participants fell ill, individual accounts highlight that illness disrupted accumulation of educational/cultural capital. During this time parents’ and teachers’ behaviour focused on keeping the young people in step with their cohort. There was, however, a concurrent loss of peer social capital that few parents or teachers addressed but was of great importance to the transplant recipients. Transplant recipients in the paediatric healthcare system were imbued with a practical habitus of passivity, because their parents and healthcare providers took dominance in health decision making. Often parents tried to shelter their children by withholding some of the medical information. Participants spoke about not knowing everything about their health. What followed was that as soon as recipients reached age eighteen, healthcare providers used various teaching modalities to prepare them for the impending transition to the adult healthcare clinic. At the time, hospital staff attempted to reposition young transplant recipients by providing them with poorly absorbed “transition training” that focused on healthcare consumerism.

Following the transition to the adult transplant program recipients reported that they were happy with the “rite of passage” because they thought they were age appropriately repositioned as adults and were in charge of their own care. What is being illuminated at that time is that transition programs were provided in a field where youth were accustomed to passivity and as such they were not involved or engaged in the process. Being cared for in the adult clinic meant

that, as one quote indicates: healthcare providers speak directly to recipients instead of their parents. The findings here highlight that there is a particular relational repositioning of young people. To this end, although habitus is not static, it is difficult to change one's disposition in a very familiar location, but potentially easier to change habitus in another location within the same field.

Much of the results reported in the first section of the results chapter have focused on the distinctiveness of young adult transplant recipients. In part two of the results chapter, following the transition to the adult transplant program behaviours and assumptions within their new field changed. Being a “good transplant patient” meant that recipients had to demonstrate maturity, which required them to alter their passive disposition and adhere to the dominant discourse of illness self-management by taking on more responsibility for their own care. As transplant recipients' habitus adapted to their new social field they demonstrate a feel-for-the-game. Participants accumulated new forms of cultural capital as their medical routines became more ingrained in their everyday practices. Working with Bourdieu's concepts, however, also implies that there is an interconnection between various fields. Players in various fields are not static objects or represent separate groups of relationships, but are also a set of interrelationships through which young adults learn their behaviours. Participants spoke about following strict medical recommendations they also talked about the difficulty of adhering to these medical practices when they socialized with their peers. Transplant recipients are navigating through both the healthcare field as well as their social/peer fields. What makes this navigation difficult is the growing tension between intended actions and unintended risks and outcomes.

Key here are questions to the type of capital transplant recipients acquire within particular fields and the extent to which such capital is actualized or valued in varying types of

institutions, whether they are affirmed or dismissed. In the clinic, accumulation of symbolic capital enables recipients to construct themselves positively and as such improves their position within their field. Alternatively, young adult social fields provide few opportunities to accumulate capital when one is ill and to be active and able is deemed culturally valued behaviour in their peer fields, representing a normative “way of being”. Hence, most participants described themselves living “normal” lives. Since participants elected to be in their bodies in a particular way, they started to conceal their existence as transplant recipients. Even though participants demonstrated an appropriate accumulation of capital within each distinct field, recipients’ relational positions within other fields lead to struggles. The type of social capital that was actualized by recipients was frequently not at stake or valuable within the healthcare field. Similarly, cultural capital gained within the healthcare field was insignificant within participants’ peer fields.

In the final Discussion chapter, I will explore recipients’ relational disposition within other dominant fields, focusing on the concept of social belonging, adherence imposed by healthcare providers, and the way young transplant patients are “normalized” and largely rendered invisible across numerous fields. I explore the logic of their practices given their histories and present realities. My goal is to demonstrate how competing fields become oppressive leading to exclusionary social arrangements that leaves young transplant recipients’ behavior inextricably linked to struggle within their various fields and impose symbolic violence.

CHAPTER 6: DISCUSSION

Introduction

The dominant theme of this study suggests that young transplant recipients struggle to position themselves favourably within fields other than health services at the time of transition into adult care. When they were younger and initially fell ill, the need for ongoing medical interventions and follow up treatments resulted in difficulties with accumulating social and cultural capital in school and with peer groups. This “capital deficit” became even more problematic when at age eighteen, recipients transitioned from a paediatric to an adult healthcare facility. At that time, transition was not only a change in location with the novelty of a new environment, but a “rite of passage” signalling a shift from youth to young adulthood. This social transition of becoming a young adult, which entailed taking on more responsibility for personal health and medical needs, competed intensely with dispositions or customary practices in peer fields. Participants’ inherent susceptibility to mirror their peers resulted in constructing themselves as “normal” healthy individuals, just like their friends. What followed was that young adults struggled with adherence to medical regimes imposed by healthcare providers as they had “normalized” their medical conditions and attempted to live like their healthy peers.

Through the process of socialization, dominant social arrangements were internalized as the perceptual schemas, dispositions and self-understandings that constitute habitus. These were imparted by parents as the guardians of medical knowledge in the paediatric field and, later, by health providers in the adult field. Indoctrination by health providers increasingly emphasized functional ability, illness self-management and responsibility. Participants wrestled with

belonging to various fields that left their behaviour inextricably linked to struggle within their competing fields. For example, participants' understood that they had to take their medications at particular times. However, for some participants their unwillingness to take medications in front of their peers meant that they skipped taking their medications, took them at later times, or alternatively, elected not to take part in social events in order to take their medications at home. This demonstrated that the competing rationalities between fields became overwhelming and led to self-exclusion from social activities. The exclusion of self from the group of youth with chronic illness is inadvertent, and for some participants what followed was a (mis)recognition of what was important. While it would make sense from the perspective of healthcare field to associate with others who have a similar health issue – in order to share capital about self-care – it is a positional risk in the peer field. Hence, in order to avoid potential risks, participants thought of themselves as “normal”, just like their peers and positioned themselves as equal players in their peer field. Being “normal” led to recipients' battles with identity, impacting practical routines and their status as young adult transplant recipients. Participants demonstrated that in an effort to align with one group – healthy young peers – they inadvertently excluded themselves to belong to young adults living with a chronic illness. In an effort to conceal their identity as a transplant recipient, part of who they were was rendered invisible across social space.

In this chapter I discuss how young transplant recipients' dispositions and their correspondence with their social world contributed and maintained the pervasive and relatively enduring effects of struggle. I will also provide suggestions on how to improve recipients' clinic experience towards realizing positive change. To do so, I will be returning to Bourdieu's key ideas, particularly the concept of *symbolic violence* as it relates to struggle within other dominant

fields. This study highlights the following concerns: 1) Young adult transplant recipients struggle with relational dispositions that excludes them from various fields of social engagement; 2) Their struggle and exclusion from various fields is symbolic and is embedded in the structure of the dominant social order of the field from where they become excluded; 3) The social order is taken up and embodied, leading young transplant recipients to practices of accommodation and “normalization”. 4) Changes in healthcare practices, attuned to person implications and peer relationships can begin to address young transplant recipients’ contradictory social positions.

I. Young adult transplant recipients struggle with relational dispositions excludes them from various fields of social engagement

Social capital and well-being.

In the results chapter, I explained that when participants fell ill, sickness disrupted accumulation of educational or cultural capital. Parents and teachers tried to keep the young people in cadence with their peers at school and often succeeded. However, participants simultaneously experienced loss of peer social capital that few parents or teachers addressed but was of great importance to the transplant recipients. Both the need for ongoing life sustaining interventions and hospitalization, as well as regular medical appointments, hindered contact between participants and their peers. Hence, participants had limited opportunities for social interactions and had trouble remaining connected with their friends. Ultimately, young transplant recipients had fewer opportunities to foster relationships, or the accumulation of social capital.

Bourdieu defines social capital as:

...the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition or in other words, to membership in a group which provides each of its members with the backing of the collectivity-owned capital, a credential which entitles

them to credit, in the various senses of the word (Bourdieu 1986, p. 248-249).

Living with a heart transplant meant that recipients had limited opportunities to establish such durable networks that allowed them to accumulate the kind of credit that would ensure supportive attention when ill.

Bourdieu is one of the main scholars responsible for bringing the concept and term social capital into present-day dialogues. Social capital is only one form of capital from which young adult transplant recipients draw. Cultural capital in the form of knowledge, functional abilities and experiences is necessary for understanding and performing the necessary health regimens. However, my findings suggest that recipients recognized social capital as being more critically important than health related cultural capital. As outlined by Bourdieu (1986), social capital is the collection of resources that allow for mutual acquaintance and the backing of a collectively owned capital. Although various forms of capital are intertwined, social capital is uniquely vital as it bridges the capital of a young transplant recipient with that of peers.

Having a sense of belonging to a particular social group, and that group's support through collectively owned capital might have an important and direct influence on transplant recipients' well being. As highlighted in the introduction of this dissertation, studies have suggested that children who received a vital organ transplant have more behavioural problems and less social competence than healthy peers (Uzar et al., 1992). What can be constructed as social competence in one study may be conceptualized as social capital in another. In this study the understanding of collectively owned capital might refer to participants "coolness" as touched on in Noah's interview, when he described spending time with his university friends who thought of themselves as "nerds". Ingrid also commented on her designation as a "nerd" when she played chess at the local pub with her peers. Or Stephan who dressed and talked like a "rapper", very

likely just like his peers. In one section of the interview, Lucas talked about how fortunate he was to have a job in a relative's business. Here collective capital could take the form of familial support secured with economic capital. This is not an exhaustive list but represents some examples from this study that illuminate collective capital of study participants.

In general, authors tend to agree that there is a theoretical and empirical link between social capital and well being (Bassani, 2009). In youth studies, the concept of social capital has a relatively long history, although it has not always been called social capital. Prior studies might refer to social networks, social support, peer support and so on. Over the past decade, a number of empirical researchers have indicated that a lack of social capital can have a negative effect on individuals' well being. These particular reports are commonly produced by studies that engage with race, ethnicity and immigration (Bassani, 2009). The understanding in these studies is that when youth belong to marginalized groups (i.e. ethnic visible minorities), family and community networks tend to be much stronger and individuals have fewer connections with other groups (Ream, 2003).

As discussed by Ream (2003) family relations among marginalized individuals tend to take precedence over possible connections with other groups, such as additional community members or peer groups. Family relations, however, do not always take precedence for some marginalized groups, such as street youth, kids with addiction, or mental health issues. It is essential to acknowledge, therefore, that dominant cultures incorporate and reproduce particular dispositions and behaviours that frequently hinder or make it impossible for marginalized individuals to establish new ties with other groups. As illuminated in the results chapter some participants talked about being bullied and marginalized and it was impossible for them to belong to a peer group during their early educational years. In this sense particular assumptions

and behaviours of some youth “othered” transplant recipients. Participants were exposed to dominant cultural assumptions about what it means to be a young person in a particular social environment and that excluded individuals like themselves. The highlighted body of literature primarily focuses on visible minority youths in America; however, the argument here is that any group that is separated (due to external forces or their own doing) from the dominant culture might experience the same negative effect of social capital. Young transplant recipients are such a group that have limited opportunities to connect with their peers and are separated from their dominant peer culture, which impacts the accumulation of social capital and can ultimately negatively influence their well-being.

My analysis demonstrates that the concept of strong family networks was also important for participants at the time when they first became ill. Recipients spoke about being thankful to their families, because without their presence and overall support they would not have been able to cope with their illness and endure the required medical interventions. This was important for them since at the time when participants fell ill, friends frequently abandoned them. Few recipients reported that they kept ties with former close friends. Individuals who were able to do so frequently talked about themselves as being very outgoing and friendly, alluding to the fact that such a disposition was instrumental in helping peers feel more comfortable around them. In secondary school, recipients talked about being bullied and marginalized based on their appearance and the “strangeness” that came with being a transplant recipient. These experiences speak to the limited opportunities to accumulate social capital and their exclusion from various fields of social engagement. By grounding these findings in contemporary research about social capital and well being, it is conceivable that young transplant recipients’ lack of connection with

their peers ultimately affects wellbeing. Not belonging to a group might influence how recipients feel about themselves and eventually impact their health.

In this case my analysis aligns with prior work that describes how social networks, social support, or social relationships impact health (Barrera, 2000; Berkman & Glass, 2000; Uchino 2004). Prospective epidemiological investigations, consistently report a relationship between social integration and all cause mortality (Berkman and Glass, 2000). A study exploring psychosocial outcomes in HIV infected adolescence transitioning to young adulthood found that the greater the social support the less psychological distress and fewer parent reported problems (Battles & Wiener, 2002). Similar results were reported in studies including children with chronic obesity, cerebral palsy, spina bifida, rheumatoid arthritis, juvenile diabetes (Varni & Setoguchi, 1993; Varni, Wilcox & Hanson, 1988; Wallander & Varni, 1989). Greater support is often associated with better illness self-management in individuals with chronic illness (Gallant, 2003) and transplant recipients in this study either had to work very hard to maintain relationships, or lacked social connections with peers altogether. Combining my analysis in this thesis with previously published work about the importance of social networks on health, it is conceivable that young transplant recipients' lack of opportunities to connect with their peers adversely affects their health in the long run.

How the paediatric clinic fosters a habitus of passivity among young recipients.

While clinic visits in the paediatric setting appeared to be straightforward for healthcare providers and parents, the findings of this study suggest that this is not the case for recipients. In the paediatric clinic, parents and healthcare providers dominated health decision-making and fostered a practical habitus of passivity in recipients. As reported in the results chapter this was

not always what participants wanted; they frequently felt that they were excluded from conversations and ultimately reported that they missed important information. On the other hand, being able to routinely look after advanced medical needs at a very young age might be an unsuitable and overwhelming expectation for any young person. Therefore, in the paediatric clinic, parents and healthcare providers' dominance in health decision-making might be an acceptable behaviour. The implication of this behaviour, nevertheless, is that it contributes to a practical habitus of passivity, which led to further isolation for transplant recipients. What followed was that participants were also disinterested in their own health and well being. The passive patient habitus developed from practical disengagement in the healthcare culture and it is conceivable that their long term exposure to the culture in the paediatric healthcare culture field contributed to an ingrained habitus of passivity.

The socially constructed habitus of many participants was reproduced, thus, established practices in the paediatric clinic were continuously reinforced. For example, relationships and interactions with healthcare providers and parents were made on the basis that all important medical information was exchanged between parents and healthcare providers. This assumptive practice was taken up and continuously excluded children from decision making without leaving space for further thought about what this could mean for the youth receiving care. Also the dominance of parents over children was perhaps part of a chain of domination that included a particular dominance of healthcare providers over parents. Everyday practices in the clinic are therefore a productive local routine, of a particular habitus that reinforces the routine in the clinic. Hence, the concept of habitus not only sheds light on the clinical practice and how the healthcare culture is embodied, but also how struggles (inequalities) are embedded in particular routines. This study demonstrates that the exclusion of recipients from important health and

medical conversations, ultimately omitted them as active participants in the routines of the paediatric clinic. This segregation from the field of active social engagement led to a habitus of disinterest and passivity, which was embodied through recipients' overall indifference to self-care.

The enduring effects of habitus at the time of transition.

Habitus refers to a set of acquired schemes of dispositions, perceptions, and appreciations, which orient individual practices and give them meaning (Bourdieu, 1992). The habitus is both a “structured structure” – influencing or constraining our future actions, and a “structuring structure” – shaping our interactions with others (Bourdieu 1990, p. 53). Hence, when young transplant recipients are being prepared through various teaching modalities to move from a paediatric to an adult transplant facility, their habits have been shaped by the “structured structures” of the paediatric clinic that function as “structuring structures” during the transition process. This means that exclusionary structures of the paediatric clinic and recipients' subsequent passive habitus was guiding participants' disposition during the transition process. It is this adopted and ingrained habitus of passivity that young transplant recipients developed in their formative years when they engaged in the transition process.

Empirical work on the impact of transition from a paediatric to an adult healthcare facility on young individuals living with chronic illness has grown over the last few years. The goal of transition is to provide continued age appropriate care for transplant recipients (McCurdy et al., 2006). Transition programs have been put in place to address young adults limited understanding of their medical condition (Higgins, 2003). Challenges during this time included “abrupt transfer, insufficient communication between paediatric and adult specialty providers

and becoming lost to follow-up” (Stabile et al., 2005, p. 363). Researchers emphasized that it is important for healthcare professionals to keep in mind that development does not stop with transition of care (Kaufman, 2006).

Evaluations of these programs, however, are not indicative of significant outcome improvements (Taylor & Bury, 2007). Remorino & Taylor (2006) reported that kidney transplant recipients who participated in a transition program were no more satisfied overall than recipients who were not enrolled in the program. About 35% of young adults still lose their kidney after transfer from a paediatric to an adult healthcare facility (Harden et al. 2012). In concordance with this study, Anthony (2009) reported that adolescents demonstrated disinterest and apathy regarding transition to adult care. This was in stark contrast to parental anxiety about their child’s eventual departure from the paediatric transplant center. Harden and colleagues’ (2012) work is seminal to this completed study as he urges healthcare providers to address young adults need for peer interaction with other young transplant recipients. His recommendations will be further discussed when reporting on implications for practice.

Overall, contemporary research on transition has lead to the development of transition programs where recipients are bombarded with medical information in order to prepare them as healthcare consumers. Findings in this study suggest that when participants turned eighteen and healthcare providers attempted to prepare them for the impending transition to the adult transplant clinic they did so in an environment where youth were accustomed to passivity. At that time, hospital staff attempted to reposition young transplant recipients by providing them with poorly absorbed “transition training” that focused on healthcare consumerism. Following the transition to the adult transplant clinic recipients felt that they were appropriately repositioned as adults, ready to take on more responsibility in order to look after their own

medical needs. The findings in this study demonstrate that transition triggered a particular relational repositioning of the young people. A change in location and its alteration of structures distributing capital, ultimately led to a change in participants' positions and their habitus. Although habitus is not static, it is difficult to change one's disposition in a very familiar location, but potentially easier to change habitus in another location within the same field.

The plastic effect of habitus was further observed when participants described routine practices during clinic visits to the adult transplant hospital where behaviours and assumptions within their new location continued to adapt. At the adult transplant clinic, being a “good transplant patient” meant that recipients had to demonstrate maturity, which required them to alter their passive disposition and adhere to the dominant discourse of illness self-management. As each transplant recipient's habitus adapted to the new social field of adult health care, they quickly developed a particular doxa, or feel-for-the-game. Most participants accumulated new forms of cultural capital as their medical routines became more ingrained in their everyday practices.

Working with Bourdieu's concepts, however, also implies an understanding that there is an interconnection between various fields. Players in various fields are not static objects nor do they represent separate groups of relationships, they are a set of interrelationships through which young adults learn their behaviours. When participants spoke about following strict medical recommendations, they also reported difficulties adhering to these medical practices when they socialized with their peers. Transplant recipients navigated both the healthcare field, and their social/peer fields. For example, recipients had to adhere to stringent medication schedules, which at times they found difficult to follow since they did not like taking pills in front of their friends.

What made this navigation difficult was the growing tension between intended actions and unintended risks and outcomes.

Young transplant recipients recognized and attempted to counter competing dominant discourses specific to each field's habitus. These included particular behaviours of aligning with one group while denying another, resisting the imposition of categories and rules, and distancing from labels and people feeling sorry for them. Like Stephan's statement:

Stephan: I hate when people feel sorry for me, because I don't feel sorry for me, I tell them. I say it's just... just whatever, I'm normal. It's normal. I needed a heart transplant so it's basically me needing a new engine in my car. If I didn't have it I'd... I'd be done.....so because I had it, it's just normal. [...] And I'm just going out, having fun.

At times, participant's valued social engagement with peers over the need to adhere to medical routines. These acts resist exclusion from one group or another and oppose the dominant discourses of being a transplant patient across fields.

This study demonstrates that resisting a particular discourse often meant accommodating others. For example, being together with friends could mean that medications are not taken as prescribed and people might be social at a bar and drink alcohol, just like everyone else. Which discourse was dominant sometimes depended on the specific field. Hence, participants' portrayed meaning of being a young transplant recipient, were acts of struggle, resistance, and accommodation depending on the field they were part of at a particular moment.

II. Recipients struggle and exclusion from various fields is embedded in the structure of the dominant social order

Dominant social order and the field of power

In the results chapter I described that study participants in the adult transplant clinic incorporated the dominant discourse of self-care, and how their practices functioned to reproduce

or resist local assumptions within the dominant field of healthcare. Many participants spoke about the effort to adhere to particular practices, which were emphasized by healthcare providers. Within these narratives, participants linked their behaviour to within-field struggle and ensuing symbolic violence, or having someone else's view imposed on them. Bourdieu (1998) described social space as field, but he also thought of this space

“as a field of forces, whose necessity is imposed on agents who are engaged in it, and as a field of struggles within which agents confront each other, with differentiated means and ends according to their position in the structure of the field of forces, thus contributing to conserving or transforming its structure (Bourdieu, 1998, p. 32).

As reported in the results chapter, Lucas was a participant who had been followed in the transplant clinic for several years prior to his interview and he had this to say:

Lucas: I would just... like, advice I would give, basically, is just, uhm, probably to do what I did in the sense that go in to your doctors by yourself. Like, even if your parents are in the waiting room, just go in there by yourself, just to get a feel for it, I guess. Be more independent...not always have your mom and dad by your side, ...I know now what to ask and what to do, stuff like that.

He had incorporated local assumptions of the dominant culture and developed a feel-for-the-game. His own assumptive priorities had adapted to the new field, and he advocated particular behaviours that were concurrent with the expectations of being a “good transplant patient”. The dominant position of healthcare providers led to a shift in Lucas's assumptions about his behaviour as a responsible recipient. However, he also viewed these behaviours as a product of personal insights accumulated over multiple encounters with health providers, not as practices that were constituted through gradual inculcation of the values of the health services field. As outlined by Bourdieu these forces transformed structures in the clinic, which are generative, shaping future clinic routines.

As the interviews progressed and study participants spoke about following strict medical recommendations, they also highlighted the challenges of adhering to medical practices.

Participants spoke about their routines of taking their medication and how they sometimes forgot to take their pills at night. Subsequently, when some recipients reflected on what was important for them and how they wanted to live their lives, they made statements like these:

Ingrid: So, I mean, how do I feel? Uhm, I feel like it sucks. [chuckles] I feel like it sucks, I feel like such is life.....uhm, [chuckling:] life sucks sometimes.....but I feel like I'd love to be healthy and, uhm, you know, sometimes I, you know, I feel like... you know? But on the other hand, you know, it's hard to look at, like, the glass full when, uhm, when I see all my friends... like, I'd have to excuse myself to go to the washroom to take my medications and, uhm, they don't have to. You know, I have to carry them around, that if I don't have them on me, uhm, if I don't have them on me then, uhm, I have to go home. I can't just sleep over at a friend's house without having everything with me.

Ingrid's narrative highlighted that the transplanted heart does not come without burden. All recipients reported on the difficult task of adhering to strict medical routines and lifestyle modifications. And since participants described that they preferred to spend time with healthy peers, they took up and reproduced local assumptions of their peers' social field, which is very distinct to the dominant healthcare discourse. Functional ability and social connectedness with friends were of importance for most participants; however, it was the need to adhere to strict medical regimes that created disruption in their everyday existence.

These observations are in keeping with current research. As transplant recipients become more responsible for their care in the adult clinic, non-adherence with medication regimes, clinical appointments and lifestyle modifications have been described as a concern following paediatric organ transplantation (Lawrence et al., 2008). Non-adherence to prescribed medication regimes lead to rejection, loss of the transplanted organ, additional morbidities and ultimately to death of the person (Chan & Person, 2007; Dobbles et. al. 2004). A recent meta-analysis indicated a non-adherence prevalence to immunosuppressants of 22.6 cases per 100 patient-years among adult transplant recipients (Dew et al. 2007). In the literature, psychological, socio-economic and treatment related factors have been identified as the most important determinants

influencing adherence. Concomitantly, findings show participants struggled with rejection by friends, independence from parents, intimacy and sexual behaviour (Kaufman, 2006) and demonstrate high risk-behaviours (DeMaso et al., 1995; Anthony et al., 2009; Suris, 2008). These studies highlight young transplant recipients' ongoing work to represent who they are and who they are not. However, competing demands and values of various social fields leads to recipients' struggle and ultimate exclusion from social engagements.

In order to further examine young adult transplant recipients' experience of struggle within competing fields and the resulting symbolic violence, it is critical to reflect on Bourdieu's work on power and domination. For Bourdieu (1998) individuals and groups only exist based on difference; "that is, they occupy relative positions in a space of relations which, although invisible and always difficult to show empirically, is the most real reality and the real principle of the behaviour of individuals and groups" (p. 31). Hence, differences among individuals and groups, in this dissertation transplant recipients and healthcare providers, are representative of their compartments and relations. To better understand the dynamics in a social field, however, Bourdieu (1998) introduces the concept of "field of power" in order to illuminate particular practices and representations.

"The field of power is *not* a field like the others. It is the space of the relations of force between the different kinds of capital or, more precisely, between the agents who possess a sufficient amount of one of the different kinds of capital to be in a position to dominate the corresponding field, whose struggles intensify whenever the relative value of the different kinds of capital is questioned" (Bourdieu, 1998, p. 34).

In keeping with Bourdieu, since healthcare providers are the keepers and distributors of cultural capital in the form of medical knowledge, they hold a dominant position over recipients. Young adults' connection with their peer fields, however, lead them to be unsettled by some of the

expectations and assumptions of their healthcare providers. What followed was that recipients inherently grappled with the relative value of various forms of capital.

The aforementioned body of research has highlighted that medication adherence is pivotal for recipients' well being. It is rational, therefore, that routines in the clinic are focused on overcoming potential barriers to not following medical routines that have been addressed in the health literature. Hence, various teaching modalities in the form of booklets, as well as one-on-one teaching sessions with healthcare providers have been implemented in the adult clinic. Such activities are performed in order to address potential pitfalls in non-adherence with critical medications. It is important to keep in mind that the argument here is not about the efficacy of medication adherence and potential negative disease sequelae. What is being objectified is the mismatch of values in relation to various forms of capital between young adult transplant recipients and healthcare providers.

Findings in this study illuminate that what is at stake in a particular field is linked to dominant positions. Domination is shaped by distinctive positions of a particular group or individuals, and their position in relation to other positions (Bourdieu, 1990). These positions, even the dominant ones, are only real because of their characteristic position and their determination it imposes on its occupants. The spaces of position, which are the structures of the field, are shaping the value and distribution of capital in a particular field. And it is the accumulation of specific capital that is at stake in a field (Bourdieu, 1990).

“Domination is not the direct and simple action exercised by a set of agents (the dominant class) invested with powers of coercion. Rather, it is the indirect effect of a complex set of actions engendered within the network of intersecting constraints which each of the dominants, thus dominated by the structure of the field through which domination is exerted, endures on behalf of all the others” (Bourdieu, 1998, p. 34).

The healthcare field, with all its members, represents such a complex network where power is no longer established by individuals, but through objectified artefacts that represent power.

Diplomas and degrees, for example, are such artefacts that have been established by institutions ensuring a dominant status of a particular group in a specific field. That is the acceptance of socially guaranteed qualifications, and the holding of socially defined positions, guarantees members social value of qualifications and the distribution of these values to others.

Furthermore, strategic practices that claim status and position in a local field may also reproduce broader discourses of “how to be a good patient” that contribute to exclusion. For example, participants’ practices of taking on more responsibility for their own medical care were successful in claiming cultural capital within their institutional setting, but at the same time unwittingly reproduced the dominant ordering of a “good patient” that relegates young transplant recipients’ social lives. For young adult transplant recipients this means that the dominant group established routines in the adult clinic. Recipients’ struggle with competing interests between being social and engaged with friends, verses the need to adhere to strict medical regimes, created a disruption in their everyday existence. Participants became ultimately excluded from various social fields and healthcare providers approach to managing the clinic in general is symbolic of their dominant power.

Gendered hexis

In the following section, I will return to Bourdieu’s understanding of hexis, or the embodiment of habitus, to further explain young adult transplant recipients’ commitment to work on their bodies. Bourdieu’s writings demonstrate that he has always been very mindful of the circumstances of how men and women move and use their bodies in very distinct ways in most cultures. It was not until later on in his career, however, that he attempted to explain how these

gendered differences of learning how to move and perceive one's own body does not occur at the cognitive level, but at a corporeal level (Burkitt, 1999). During this time, the body was important for Bourdieu, as gendered norms and particular gendered dispositions are embodied. Hence, the social is embodied and mapped on the body for further inspection.

Bourdieu's concept of *hexis*, or the embodiment of *habitus*, is important here as gendered *habitus* signifies the "social construction of masculinity and femininity that shapes the body, defines how the body is perceived, forms the body's habits and possibilities for expression, and thus determines the individual's identity – via the body – as masculine or feminine" (Krais, 2006, p. 121). In keeping with Bourdieu (1997), gender is an "absolute fundamental dimension of the *habitus* that, like the sharps and clefs in music, modifies all the social qualities that are connected to the fundamental social factors" (Krais, 2006, p. 128). Hence, it is essential to further reflect on a gendered specific *hexis*, as it is a vital component of an individual's self, as it "touches the individual in an aspect of his/her self that is generally seen as 'pure nature: the body'" (Krais, 2006, p. 121). Undeniably, it is this orientation to the body that the concept of gender becomes "deeply and firmly" affixed in the *habitus* (Krais, 2006, p. 121), and as such is apparent in the form of *hexis*.

The results of this study suggest that young transplant recipients reproduced culturally valued assumptions about what male or female bodies are supposed to look like. All male study participants reported that their scars did not bother them and they rarely thought about their incisions. It is conceivable that such comments reflected the prevailing assumption that scars on a male body might be interpreted as masculine, in keeping with being tough. Additionally, young men don't usually wear necklines low enough to reveal scars. Alternatively, female study participants thought carefully how best to conceal any scars and to represent their body in a

particular way. All participants were concerned with the relationship between body, image, and how this might affect potential peer relations. In other words, appearance of a person's body is pivotal to social acceptability. This seems to reflect a popular assumption that the body is a reflection of the self and the person's inner character or personality will shine through the outer appearance. Ingrid's relief at her attractiveness to young men suggested that many young women recipients feared their scars might be viewed as flaws and could disqualify them as lovable. On the other hand, recipients assumed that concealing scars and representing an enhanced appearance presented a body that was more congruent with their "true" selves. This concealment was necessary to transform the self by constructing a new "normal" through the representation of their body in a particular way.

More recently, however, scholars have further examined the concept of field and have claimed that it can provide an avenue to illuminate some of the particularities and interconnectedness between men and women in contemporary social life (Mottier, 2002). Other theorists have claimed that field might be useful in explaining how gendered norms and practices vary between men and women, within different classes and groups, and within their respective social fields (Allard, 2005; Hills, 2006; Huppatz, 2009). Thorpe (2009, 2010) adopted a gendered reading of male and female snowboarders in the athletic field of snowboarding. She highlighted that the embodied practices of snowboarders demonstrated that the type of capital that was at stake for them was not so much based on gender but influenced by individuals' position and structure of the field, as well as a commitment to a particular lifestyle. For example, an interest in fashion might potentially be interpreted as a feminine disposition. Male snowboarders, however, showed a strong interest in fashion and went to great expenditures to appear a certain way. Having a strong fashion sense might not necessarily be interpreted as masculine in other fields.

Within the snowboarding field, however, it represented a masculine attitude of nonconformity, including distinctive use of colours such as hot pink.

Thus, Bourdieu's concept of field is useful in moving beyond a gender dichotomy. According to McNay (1999) to introduce such a particular reading of the social construction of gender identities, highlights a more fluid view of feminine and masculine dispositions rather than separate and opposing concepts. Conceptualizing feminine and masculine gender as a malleable model implies that the expression of each is dependent on place, and is therefore shaped by specific social spaces. Hence, Thorpe (2010) argued that rather than visualizing the snowboarding culture as a field bound by masculinity, her work focused on various forms of masculinities that may be expressed depending on the particular field.

This study demonstrates that a participant's social field also included a particular habitus that might not be associated with masculine norms. Most male study participants demonstrated a fashion forward appearance. For example, Noah demonstrated his self-representation of a "normal second-year university student". His hairstyle, moderate facial hair and trendy t-shirt represented a particular "hipster look" currently popular with young people. In comparison, Peter also thought of himself as a "normal" young person by wearing a baseball cap, baggy clothing and a hoody. His way of dressing was very distinct from Noah's but both young men adhered to a particular fashion trend within their distinctive social field. Style is a form of self-representation and in keeping with Bourdieu is an indicator of class or group membership because trends in consumption seemingly correlate with an individual's fit in society. And an interest in fashion, particularly within young transplant recipients' respective social field, might be a masculine disposition after all.

III. The social order is taken up and embodied, leading young transplant recipients to practices of accommodation

Being “normal”

This study highlights that young transplant recipients resisted being labeled in a particular sick role within their social fields. What followed was that recipients generated their “new normal” by constructing themselves in a positive public and self-image. Being functionally able was important within their respective peer fields and since most participants lived very healthy active lives; it allowed them to accumulate cultural and social forms of capital. Furthermore, by accumulating these forms of capital, participants were able to construct themselves positively within their social field. In addition, appearance was very important for participants and for some female transplant recipients this also meant that they changed the way they dressed in order to conceal their large surgical scars on their chests. Participants incorporated the dominant culture within their peer field, a (mis)recognition of what might have been more helpful for them in order to avoid an altercation with identity and self-worth.

Similar behaviours are seen in individuals living with chronic illness or forms of physical disabilities where social relationships and self-image (clothing, style, language) are impacted by strict medical treatment regimes. For example, current treatment recommendations for juvenile diabetes include lunchtime injections of insulin. Swift (1997) has reported that some adolescents will not give themselves their injection for reasons of “fitting in”. Alternatively, some prioritize their social time with their friends over administering a particular treatment and thus evade proper management their disease (Suris, Michaud, & Viner, 2003). A systematic review of qualitative studies including young transplant recipients reported that they struggled with their identity, as well as managing their medical demands (Tong et al. 2009). In adolescents with

chronic illness conditions where individuals need to adhere strictly to medications, or use inhalers (asthma or cystic fibrosis), insulin pen and glucometers (diabetes), treatments are frequently dependent on their acceptability in adolescents' competing social lives (O'Callaghan & Berry, 2000). This means, similar to young adult transplant recipients, they are constructing themselves in a positive public image.

This study further demonstrates that healthy young bodies are culturally valued and participants reproduced these social values. Staying in shape through exercise was important for many young men who participated in the study. Female recipients also spoke about dieting in order to have a body that was more in keeping with what was deemed culturally acceptable. Participants, however, also spoke about negative public experiences that ultimately influenced how they thought about their bodies. At times, participants reported being stared at, or were asked about their scar by strangers. Female study participants, especially, reacted very strongly to this intrusion by strangers into what most of them considered a very private matter.

Not being able to be like any other young woman, due to their prominent chest scars, for some participants meant that they considered themselves potentially unlovable. Hence, for some young women in this study, these values impacted self-assessment of their worth. Alternatively, other participants reported that they did not hide their scars and a few actually wore revealing clothing during the interview process. By doing so they demonstrated a very confident demeanour. These women, however, also frequently covered their scars with their arms during the interview, performing a balancing act of both revealing and concealing, ultimately having to own up to their scars but also demonstrating feminine capital.

Key here are questions to the type of capital transplant recipients acquire within particular fields and the extent to which such capital is actualized or valued in varying types of

fields, whether they are affirmed or dismissed. The focus in this particular section of the thesis is not on formal institutions – like the paediatric and adult healthcare facilities – that encourage transplant recipients to adhere to strict cultural norms. Rather, I seek to explore participants’ reproduction of cultural and social capital within their respective peer fields that enabled them to imagine and establish a sense of normality. Hence, the study provides young transplant recipients’ accounts of ordinariness expressed during the interview in order to capture the ways in which being normal was presented by study participants.

Young adults’ social fields provided few opportunities to accumulate capital while ill. To be active and able was clearly deemed culturally valued behaviour in their peer fields, representing a normative “way of being”. Hence, most participants invested considerable energy and effort into living active lives. This lifestyle enabled them to perceive themselves as not being any different to their peers, and they described themselves as living “normal” lives. Since participants elected to be in their bodies in a particular way, they started to conceal their existence as transplant recipients. Even though participants demonstrated an appropriate accumulation of capital within each distinctive field, recipients’ relational positions within other fields, mainly the healthcare field, led to struggles. The type of cultural and social capital that was actualized by recipients was frequently not at stake or valuable within the healthcare field. Similarly, cultural capital gained within the healthcare field was insignificant within participants’ peer fields.

Institutional and non-institutional practices and the accumulation of various forms of capital led participants to imagine and perceive themselves in a distinct way. They established practices that lead to the accumulation of “normal” healthy development, “normal” functioning, “normal” health and so on. Foucault (1977) famously noted:

“The judges of normality are everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the social worker-judge; it is on them that the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to it his body, his gestures, his behavior, his aptitudes, his achievements” (p. 304).

Routines in the adult transplant clinic, with its policies and practices, oriented towards adhering young transplant recipients to strict medical recommendations are inextricably linked to implementing a particular norm. A norm that has been established by the dominant group in the healthcare field and as previously discussed conflicts with young transplant recipients understanding of their lives.

Within their own social field, young adult transplant recipients positioned themselves as “normal”, healthy and capable individuals. As established in the results section, recipients struggled and fought to be more like their peers. In an effort to not be seen as different by their peers and to belong to a desired social field, participants reproduced local assumptions of what is culturally valued among *healthy* young adults. They behaved in particular ways – not taking their medication in front of their friends, drinking socially, going out to pubs – a (mis)recognition of what was socially important.

Participants ultimately began to hide or negate particular facets of existence as a transplant recipient. Inevitably, transplantation is associated with physical and emotional challenges, as most participants acknowledged during the interviews. Since participants elected to represent their bodies and practices in socially acceptable ways, they demonstrated a reluctance to share their innermost concerns and feelings with others. This logic of practice was also cultivated during their formative years as young transplant recipients, where some participants were frequently bullied or marginalized based on appearance and because of their medical condition. Although habitus was not immutable, participants’ dispositions following

their transition to the adult clinic highlighted its enduring effects. Participants continued to think of themselves as isolated and alone and felt that no one understood what they were going through.

Young transplant recipients internalized negative perceptions about themselves and their bodies, which might also have contributed to their marginalization and exclusion. From a very young age, most individuals internalize particular values or understandings of different bodily forms. People learn to appreciate what different forms or expressions are more masculine or feminine, beautiful or plain and so on. As I have discussed in the results chapters, most study participants demonstrated a particular doxa, or a feel-for-the-game, as they spoke about their commitment to work on their bodies or physical appearance, a form of symbolic capital, which ensured them a favourable position with the dominant discourse of self-management.

Participating young women also included dieting, a form of body-work, in order to comply with socially acceptable norms of what a female body should look like. Values assigned to bodies, that include body properties (body shape, skin color, speech patterns, body movement, comportment) and also body expressions (clothing and accessories, gesture, stylizes of speech, and habitus) tend to be more or less collectively understood within a given culture, bearing in mind some variations. Participants in this study took up local assumptions of what a healthy body ought to look like, and they reproduced what was deemed socially valuable. By doing so, recipients could have contributed to or reinforced an esthetic of the body, which might in turn have lead to their own marginalization and exclusion if one does not fit with a narrow understanding of feminine beauty.

For Bourdieu (2001) the term bodily hexis, or the embodiment of habitus, suggests that the social imagery of the body is poised to express the “true nature” of a person (p.64). This

implies the linking of the physical and the moral properties and is the “language of nature”, which is to reveal what is most true about a person (Bourdieu, 2001, p. 64). Hence, it is in fact an understanding of social identity misrecognized as natural. Moreover, individuals internalize and draw from these principles when assessing their own values. Young adult transplant recipients’ wounded bodies do not comply with the standard of legitimate bodies, nor do their scars comply with hegemonic notions of the feminine body. The marginalization of the young transplant body is confirmed in the gaze or avoidance of strangers and was reproduced when participants thought of themselves as potentially not lovable. The body here is the sight of social power where the receiver recognizes the categories and what a legitimate body should look like and applies to one’s own form. The power could not exert its effect unless the categories of perception were not recognized by both perceiver and perceived (Bourdieu, 1984, p. 207).

Being lost in the new “normal”

A number of recipients reported that no one understood them. They claimed that only someone who had a heart transplant could know what it is like to live with a transplanted heart. Hence, only other transplant recipients were truly able to understand the experiences and challenges they were going through. Participants expressed that living through heart transplantation cannot be compared to any other medical condition. They reported it was very emotional, distressing, and physically demanding. Similar findings were reported in a study that included adult transplant recipients who also spoke about the difficulty of living with a transplanted heart. They stressed that most “others” do not understand what it means to endure these lifesaving procedures and they acknowledged that the heart does not come without its burden (Mauthner et al., 2012). Sadala and Stolf (2008) reported similar results when investigating transplant recipients experience of living with a new heart.

This study demonstrates that all recipients felt their experience was unique. It was common for participants to express feelings of loneliness and having no one to talk to who has been through a similar experience. When some participants declined to make friends with other transplant recipients, because they wanted to be with ‘normal’ people or they felt that they had very little in common with other recipients, this suggested that participants had internalized relations of symbolic violence. Following Bourdieu’s understanding of symbolic violence - which means imposing a dominant view on others - study participants had internalized the view imposed on them and acted on it by not seeking other transplant recipients for friendship.

There is a need for greater elaboration of how social and cultural context shape, and to a certain extent conceal, transplant recipients’ images of themselves. Status is a salient issue for young transplant recipients. This study has demonstrated that current approaches in the healthcare field failed to adequately support young recipients in developing competencies that have good long-term efficacy in adhering to medical regimes. In general failure in developing successful health promotion strategies for adolescents is evident in gender-specific tobacco programs. Prevention is directed at female tobacco smokers with the underlying assumption that girls smoke because they lack self-esteem (Gray et al., 1997; Michel & Amos, 1997). Women are positioned in a passive way, rather than viewing smoking as an active choice, taken up by young women in order to navigate the field of peer relationships (Poland, 1995; Baillie et al., 2005). Hence, smoking can be seen as way of demonstrating identity.

Smoking can “both convey information about who you are and who you are not – contingent on when and where you smoke and with whom” (Nichter et al., 2006, p. 234) and is therefore an exercise in distinction and self-control (Haines et al., 2009). Such understanding is moving away from psycho-social or peer driven behaviours and provides conceptual

understanding of how adolescent behaviours like drinking, smoking and drug use, are much more than simple teenage rebellions and experiments. They can serve as cornerstones for defining oneself, establishing a particular status, and establishing differences within adolescents' social field (Haines et al., 2009).

This study suggests that the accumulation of a particular social and cultural capital enables young adult transplant recipients to shape their particular identity. They are able to demonstrate who they are – healthy, functional individuals – and who they are not – transplant recipients who struggle with self-care. By concealing their medical condition and ultimately their needs, participants also hide part of their own identity. The concept of capital further demonstrates that young adult transplant recipients' suppression of their medical condition is sustained regardless of healthcare providers' ongoing health promotion during clinic visits. An effort to be “normal” confers identity, capital and status during the transition to young adulthood.

In the end, participants demonstrated that they felt nobody understood their experience and ultimately their suffering, because only individuals who have been through similar events would be able to relate. Recipients felt that they don't belong with other people in the adult transplant clinic, because most other patients were significantly older and understandably lived very different lives. Hence, since these young adult transplant recipients represented themselves as “not like everyone else in the clinic”, they worked very hard to demonstrate that they belonged with healthy “normal” young individuals. Constructing this particular identity, which ultimately conferred a particular status among their peers, also required extensive work in denying who they were not. Participants put up a strong front but eventually cried alone.

IV. Changes in healthcare practices, attuned to person implications and peer relationships can begin to address young transplant recipients' contradictory positions

Change in the young adult transplant clinic

It is important to clarify potential misinterpretations about arguments in this chapter, as this might otherwise lead to a wrongful objectification of healthcare providers. Healthcare providers' efforts to encourage transplant recipients to adhere to strict medical recommendations, as well as their efforts to foster self-care in these individuals, is certainly based on empirical evidence. As previously discussed, medical research highlights the importance of adhering to strict medication regimes in order to prevent rejection, graft loss, and additional morbidity (Chan & Pearson, 2007; Dobbles et al., 2004). This study demonstrates, however, that young adult transplant recipients struggled with these demands, as they attempted to cope with relational dispositions from various fields of social engagement. What might improve recipients' transplant experience is a significant change in how care to this particular group is being delivered. The argument here is that a change in healthcare practices might begin to address participants' contradictory positions. This is not accomplished by telling individuals what to do, but through broader approaches that enable recipients to connect with people like themselves and stimulate a habitus of adherence to the socially acceptable norms within the healthcare field.

This study demonstrates that the medical establishment promoted the accumulation of cultural capital in the form of medical knowledge and self-care. A dominant discourse that was taken up by most young transplant recipients and reproduced in everyday practices in the adult transplant clinic, and at home in the form of being more responsible for ones' own medical needs. It was, however, participants' relational dispositions within their dominant peer fields that undoubtedly established forms of struggle and exclusion. These dominant practices of self-care

and accumulation of medical knowledge are so deeply ingrained into recipients' cultural discourses and are reproduced at every turn – the clinic, by family members, in popular culture of what it means to be a “good” transplant patient – that individuals take these struggles as a given. Everyday transplant recipients live with struggles due to competing interests without ever reflecting on them. Young adults have little understanding of the arbitrary nature of what is expected of them as “good” transplant patients or that things do not have to be in a particular way. For example, as suggested in this study the development of a young adult transplant clinic is needed in order to foster much needed peer interaction, which could start to address the issue at hand.

Symbolic violence, through insisting on particular medical behaviours and clinic routines, is enacted by the medical community and is potentially hurting young transplant recipients. These routines and expected behaviours are taken up and reproduced by individuals, including recipients who may suffer unintended consequences. Overall, the damage is unintentional, as the values and practices in health care are not particularly focused on anything but maintenance of the transplanted organ and recipient survival. It is difficult for actors in one field to understand the values and practices in another field, even if they have all been young once themselves. Simply by showing interest in recipients' circumstances, and acknowledging and respecting that they are young “normal” individuals with desires and concerns could one start to address the issues at hand.

An improvement in recipients' experience can only be achieved through a collective recognition by healthcare providers that the status quo of solely focusing on medication adherence is not ideal. Healthcare providers need to jointly demonstrate a willingness to change and improve. Certain appropriate clinical settings could be a potential place to start, for example,

the focus could be more attuned to personal implications and peer relationships. Also, by establishing much needed peer interaction, recipients would be given an opportunity to have a dialogue about social survival.

Chapter Summary

For Bourdieu, fields refer to structured systems of social positions that are occupied by individuals or institutions that are engaged in similar activities. As previously discussed, these fields are structured internally and they are sites of struggle for position, which seem to imply power struggles. “In order for the field to function, there have to be stakes and people prepared to play the game, endowed with the habitus that implies knowledge and recognition of the immanent laws of the field, the stakes, and so on” (Bo, 1993, p. 72). Young adult transplant recipients are such individuals reproducing local assumptions of dominant discourses within their respective peer fields. What was at stake for participants was the longing for social connectedness, functional ability and the representation of their bodies in particular ways.

These were all forms of symbolic capital that were of great importance for study participants. Social capital, however, is uniquely vital as it bridges the capital of a young transplant recipient with their respective peers. I have demonstrated in this chapter that having a sense of belonging to a particular social group, and the groups backing through collectively owned capital might have an important and direct influence on transplant recipients’ well being. Nevertheless, a dominant healthcare culture, embedded with particular routines of healthcare consumerism, ultimately demonstrated a habitus that embodied participants’ struggle within competing fields. As such, every undertaking, disposition, commitment, or aesthetic choice that

countered an assumption or dominant discourse of what young transplant recipients ought to be like, needed to be considered as moments of struggle and resistance.

Various principles that led to these struggles and resistance were frequently internalized by young transplant recipients when assessing their own values. This study demonstrated that the accumulation of a particular social and cultural capital enabled young adult transplant recipients to shape their particular identity. They were able to demonstrate who they were – healthy, functional individuals – and who they were not – transplant recipients who struggled with self-care. By concealing their medical condition and ultimately their needs, participants also hide part of their own identity. The concept of capital further demonstrated that young adult transplant recipients' suppression of their medical condition was sustained regardless of healthcare providers' ongoing health promotion during clinic visits. An effort to be “normal” conferred a discussion of identity, capital and status of young adulthood transplant recipients.

CHAPTER 7: CONCLUSION

Overview of Study

The goal of the study was to use an innovative visual interview technique to explore how young adults resituate themselves within the logics of a new field of health service consumption; how they re-inhabit their bodily practices of self-care; and how they are inculcated with new forms of capital as patients in an adult health care facility. In order to explore young adult transplant recipients lived experience growing up with a transplanted heart and transitioning into young adulthood, twelve interviews were conducted with recipients who have recently transitioned from Sick Kids Hospital to the outpatient transplant program at the University Health Network. The study was conducted using qualitative visual methods and explored participants' narratives. Drawing from the work of Pierre Bourdieu and visual methodologists Sarah Pink and Christian Heath, I audio/video recorded twelve study participants and analyzed spoken words and body gestures. My methodology involved an iterative, three part process to capture the salient features of individuals' social interactions in everyday life to address the research objective, which included critically exploring the relationship between visual and verbal data

Data analysis was shaped by Bourdieu's theory of practice and how habitus and its interconnection with field and capital provided a framework for conceptualizing the social world of transplant recipients. Thus, individual position within a particular field was co-constituted by habitus in terms of arrangements of capital and how these resonated with the structuring rules within a particular field. Bourdieu's approach to analyzing research data was used to provide a theoretical lens; his concepts were used to enhance my analysis of the interplay between the

subjective social and the objective self. To further overcome the dichotomy between body and self, interview content was reviewed for participants' life circumstances, and videos provided information about the body and embodiment of capital.

The structures of data analysis, however, were theoretically driven by techniques used in visual methodology. In visual methodology the assumption is that images and words contextualize each other, forming a set of different representations evocative of emotions and experiences. This implied an analytical process of making meaningful links between different experiences, visual data and other objects. Images and words contextualized each other, forming a set of different representations and strands of the phenomenon.

The data analyses suggest that young adult transplant recipients' biography was shaped by relational dispositions within other dominant fields. What was at stake for participants was the longing for social connectedness, functional ability and the representation of their bodies in the form of embodied capital valued by peers. I have reported that having a sense of belonging to a particular social group, and the groups backing might have an important and direct influence on transplant recipients' well being. Nevertheless, a dominant healthcare culture, embedded with particular routines of healthcare consumerism, emphasized behaviours that competed with participants' social peer environment. What followed was that participants' struggled with these opposing demands.

I argued in the Discussion chapter that young transplant recipients recognized and attempted to counter competing dominant discourses specific to each field's habitus. These included particular behaviours of aligning with one group while denying another, resisting the imposition of categories and rules, and distancing from labels or practices that prompted others to feel sorry for them. These acts resisted exclusion from one group or another and opposed the

dominant healthcare discourses of being a transplant patient across fields. Every undertaking, disposition, commitment, or aesthetic choice that countered the dominant discourse of what young transplant recipients ought to be like were considered moments of struggle and resistance.

Various principals that led to these struggles and resistance were frequently internalized by young transplant recipients when assessing their own values. They were able to demonstrate who they are – healthy, functional individuals – and who they were not – transplant recipients who struggled with self-care. This included that participants concealed their medical condition and ultimately their needs, which masked part of their own identity.

What the findings in this study illuminate is that what is at stake in a particular field is linked to dominant positions. Domination is shaped by distinctive positions of a particular group of individuals, and their position in relation to other members in the field. The spaces of position, which are the structures of the field, are shaping the value and distribution of capital in a particular social environment. And it is the accumulation of specific capital that is at stake in a field. Healthcare providers who demonstrated a dominant position in this study promoted the accumulation of medical knowledge and an increase in self-care, which are forms of cultural capital. What this study demonstrates, however, is that young adult transplant recipients' suppression of their medical condition - since they "normalized" their illness - was sustained regardless of healthcare providers ongoing health promotion during clinic visits. Recipients' efforts to be "normal" hindered a useful discussion with healthcare providers about identity, practical routines and their status as a young adulthood transplant recipient.

In the end, participants indicated that they felt nobody understood their experience and ultimately their suffering, because only individuals who have been through similar events would be able to relate. Recipients confided they did not belong with people in the adult transplant

clinic, as these patients were significantly older and understandably lived very distinct lives. Hence, since these young adult transplant recipients are not like everyone else in the clinic, they work very hard to demonstrate that they belong with healthy “normal” young individuals. Constructing this particular identity, which ultimately gives them a particular status among their peers, also requires extensive work in denying who they are not. This leads to an image where they put up a strong front and eventually cry alone.

Healthcare providers’ efforts to promote adherence to strict medical routines unintentionally contributed to young transplant recipients’ struggles and powerlessness. Routines in the clinic were taken for granted, everyday practices became (mis)recognized as standards for normal or successful behaviour for young transplant recipients that were closely linked to normal conduct. Young adults efforts to be good patients were realized in all of the expressions of self-evaluation, avoidance and exclusion revealed in study participants’ accounts. Functional ability and social connectedness with friends were of importance for most participants; however, it was the need to adhere to strict medical regimes that created a disruption in their everyday existence. These practices hurt young transplant recipients precisely because they are taken up and reproduced by individuals, including recipients who may suffer unintended consequences. Participants accepted the fact that being part of their peer environment was incompatible with their need to adhere to medical regimes and these assumptions were taken up and shaped how recipients saw the world and acted in it. Their history determined how they understood their social environment and by reproducing these systems they contributed to their difficulties in their own daily routines. Overall, the damage is unintentional, because the values and practices in health care are focused on nothing but maintenance of the transplanted organ and recipient survival. It is difficult for actors in one field to understand values and practices in another field.

However, simply by showing interest in recipients' circumstances, and acknowledging and respecting that they are young "normal" individuals with desires and concerns, health providers could start to address the issues at hand.

Theoretical Contributions

Bourdieu's theory of practice provided the theoretical underpinning for exploring recipients' stories. This theoretically informed study captured study participants' accounts of what it is like to be a young adult who received a heart transplant during childhood and ultimately transitioned from a paediatric to an adult healthcare facility. Young adult transplant recipients lived experience is grounded in theoretical assumptions of habitus, field and capital lending insight to interview and visual data. The study provides insight into the complexity of being a young adult living with a transplanted heart. Findings demonstrate participants' struggle with relational dispositions and how they at times were excluded from various fields of social engagement. For example, I explained that when participants fell ill, sickness disrupted accumulation of educational or cultural capital. Parents and teachers tried to keep the young people in cadence with their peers at school and often succeeded. However, participants simultaneously experienced loss of peer social capital that few parents or teachers addressed but was of great importance to the transplant recipients. Both the need for ongoing life sustaining interventions and hospitalization, as well as regular medical appointments hindered contact between participants and their peers. Hence, participants had limited opportunities for social interactions and had trouble remaining connected with their friends. Ultimately, young transplant recipients had fewer opportunities to foster relationships, or the accumulation of social capital.

This study is the first that interviewed young adult transplant recipients and applied Bourdieu's theory of practice to provide theoretically informed accounts of recipients' experiences. Participants in this study recognized and attempted to counter competing dominant discourses specific to each field's habitus. These included particular behaviours of aligning with one group while denying another, resisting the imposition of categories and rules, and distancing from labels. These acts resisted exclusion from one group or another and opposed the dominant discourses of being a transplant patient across fields. Recipients showed resistance and struggled with competing dispositions, commitments, or aesthetic choices by countering the dominant discourse of what young transplant recipients ought to be like. These struggles were pointed out by participants in this study as an integral part of living with a transplanted heart. What followed was that recipients felt that nobody understood the ongoing fight and burden of living with a transplanted heart.

This study also reveals that fields allow a particular reading of social construction of gender identities, highlighting a more fluid view of feminine and masculine dispositions. What followed was that participants had a particular aesthetic and represented their bodies in particular ways based on the dominant cultural assumptions within their respective peer fields. Style is a form of self-representation because trends in consumption seemingly correlate with an individual's fit in society, or their belonging to a particular peer group. Additionally, within their own social field, young transplant recipients positioned themselves as "normal", healthy and capable individuals. As established in the results chapter, recipients struggled and fought to be more like their peers. In an effort not to be seen as different by their friends and to belong to a desired field, participants reproduced local assumptions of what was culturally valued among

healthy young adults. They behaved in particular ways, a (mis)recognition of what they deemed important.

The study provides insight into how healthcare providers are the keepers and distributors of cultural capital and how they are holding a dominant position over recipients. The medical establishment promoted the accumulation of cultural capital in the form of medical knowledge and self-care. A dominant discourse that was taken up by young transplant recipients and reproduced in everyday practices in the adult transplant clinic, as well as at home in the form of taking medication, making medical appointments and so on. It was, however, participants' relational dispositions within their dominant peer fields that undoubtedly established forms of struggle and exclusion.

These dominant practices are so deeply ingrained into recipients cultural discourses and are reproduced at every turn that individuals take for granted these struggles as a given, live them everyday without ever reflecting on them, and have little understanding of their arbitrary nature or that things do not have to be in a particular way. This form of symbolic violence enacted by the medical community is counterproductive precisely because it is taken up and reproduced by individuals, including young transplant recipients to which it can exert the most damage.

As healthcare providers continuously work on improving services for young transplant recipients, their efforts focus on self-care and medication adherence. These approaches, however, are undertaken in a social environment where recipients struggle with their identity. These young adults battle very existential questions of “who am I as a person” and also “who do I want to be”. But while struggles of identity are consistent with the development of healthy youth and young adults, during this time peer groups are the more important influence and the key social arena (West, 2009). Young peoples identities are shaped by wider cultural influences (West, 2009) and

healthcare providers in the transplant clinic would be able to better support their patients by acknowledging recipients struggle with relational dispositions within competing peer fields.

Young adult transplant recipients' embodied struggles allude to the pervasive and damaging effects of not belonging to a particular social field and ultimately adopting a disposition of exclusion. Recipients, like other individuals who have been excluded from dominant social fields, do not choose domination, submission and ultimately resignation to the dominant forms in their lives. Healthcare providers dominant disposition and the effects of symbolic violence are taken up and reproduced by recipients and exerted through their habitus, which operates at an unconscious level.

All individuals caught up in a particular field reproduce particular hierarchies regardless of their status in the field. Nevertheless, this study provides insight that, through a collective misrecognition, harm is being done to young transplant recipients. As Bourdieu (1997) states, practical knowledge is "profoundly obscure to itself" (p. 171). Young transplant recipients' struggles are being fashioned out of everyday practices in the transplant clinic or at home. And the results of the study demonstrate that these different forces are a product of deeply inculcated understandings of the social order that recipients share with others. Exclusion and eventually loneliness are an enduring effect of power, inscribed into the bodies of recipients in the form of schemas of perceptions and beliefs about the world and what is real or possible.

The most significant contribution of this study is that young adult transplant recipients struggle with relational dispositions and are excluded from various fields of social engagement. Their struggle and exclusion from various fields is symbolic and is embedded in the structure of the dominant social order of the field from where they become excluded. The social order is taken up and embodied, leading young transplant recipients to practices of accommodation and

“normalization”. Changes in healthcare practices, attuned to personal implications and peer relationships, can begin to address young transplant recipients’ contradictory positions. What was at stake for participants was the longing for social connectedness, functional ability and the representation of their bodies in particular ways. In the end, this study provided a nuanced understanding of different expectations between two different social fields and their cultural experiences.

Practice Contributions

Findings of this study need to be incorporated in our daily care for patients, in order to provide evidence-based practice. Research projects that are focused on clinical needs will result in “more effective treatments, more efficient use of scarce resources, transparency and accountability in clinical decision making”, which will result in empowerment of both clinicians and their patients (Sandelowski, 2004, p. 1369). Therefore, when developing transition programs and establishing routines in the adult clinic, in order to provide evidence-based practice, it is important to include information from more specific qualitative health research. When improving healthcare delivery for young adult transplant recipients, including findings from this study, means incorporate knowledge that is “grounded in human experience” (Sandelowski, 2004, p. 1368). In the end, conducting person-centered research, and incorporating the findings in future transplant programs is an opportunity to provide evidence based care and truly create mindful healthcare approaches (Sandelowski, 2004).

The findings in this study point to the need to overcome dichotomies between agency and structure and how they combined shape individuals biographies. It is through this collection of information that one was able to understand how competing social environments lead to struggle

and exclusion of transplant recipients, which was embedded in the structure of the dominant social order. This study captured knowledge and healthcare seeking behaviours in young adult transplant recipients during a transitional period of time. Specific individual health experiences were captured, and demonstrated the complex needs and experiences of these individuals. Current transition and clinical programs failed to consider attitudes and perceptions of the individual person in transition. In the end, the conducted research illuminated young recipients' interests, struggles and their individual nature, which has a significant impact on their lives as young transplant recipients. Programs need to be implemented that are truly meaningful for young adult transplant recipients.

What is needed is an approach that acknowledges recipients' struggle with their relational dispositions and fosters peer interaction in order to improve the lives of young adults. For example, participants in this study talked about taking on more responsibility for their medical care. Numerous studies, however, have demonstrated that young adults are still the group with the highest rejection rate of all transplant recipients, which is frequently related to non-adherence to strict medication regimes (Chan & Person, 2007; Dobbles et. al. 2004). Hence, the kind of behaviours that recipients are portraying during clinic visits – the readiness to take on more responsibility for personal health and medical needs – is not always easily followed when one is engaged in a different social field. Young adult transplant recipients' social environments, with a particular dominant peer culture influenced recipients' self-care behaviours. Simply by showing interest in recipients' circumstances, and acknowledging and respecting that they are young “normal” individuals with desires and concerns one could start to address the issues at hand.

In order to significantly improve transplant recipients' illness experience, healthcare providers have to rethink how care is being provided. What is needed is the introduction of

young adult clinics. As reported by Harden (2012) there is a need for a dedicated young adult transplant clinic, bringing together young recipients with a median age of twenty-two years. Such clinics would provide an opportunity for much needed peer interaction, which is non-existent in the current clinic environment. Harden (2012) argues for moving the young adult clinic away from the hospital setting into a college or sport center in order to mimic the environment of a youth club, to catalyze peer interaction. What is needed is an integrated transition program *with* a young adult care clinic. As Harder (2012) and his team have demonstrated such undertaking has led to a reduction in the rate of transplant loss, reduced morbidity and has led to fewer admissions.

Summary of Recommendations
<ul style="list-style-type: none"> Healthcare providers interest in recipients' social circumstances and acknowledging and respecting that they are young "normal" individuals with desires and concerns could start to address the issues at hand.
<ul style="list-style-type: none"> Developing more robust transition programs that acknowledge recipients passive habitus and their struggle with taking on more responsibility for personal health and medical needs
<ul style="list-style-type: none"> Transition occurs at a time when recipients struggle with their identity, which is shaped by wider cultural influences. Healthcare providers in the adult transplant clinic would be able to better support their patients by acknowledging recipients struggle with relational dispositions within competing fields.
<ul style="list-style-type: none"> There is a need for dedicated young adult transplant clinics, by bringing together young recipients with a median age of 22 years, such clinics would provide an opportunity for much needed peer interaction, which is non-existent in the current clinic environment.
<ul style="list-style-type: none"> Use of innovative research techniques for future projects with young adults that emphasize young peoples own perspectives and ensuring that their own voices are heard.

Research Contributions

The execution of this study might contribute to the design of future research projects that include individuals manoeuvring the healthcare system and their struggle with relational positions from various fields of social engagement. There are limited texts outlining how to best incorporate Bourdieu's theory of practice into a particular study. This study used a novel study design by combining visual methods with Bourdieu's concept of habitus, field and capital. In his

work “Distinction” Bourdieu highlights findings that are rich with typical approaches used in sociological work. He incorporated interviews, surveys, graphs, maps, and charts to illuminate culture in a particular milieu.

The notions of social space, symbolic space, or social class are never studied in & for themselves; rather they are tested through research in which the theoretical and the empirical are inseparable and which mobilizes numerous methods of observation and measurement – quantitative, qualitative, statistical & ethnographic, macro-sociological & micro-sociological (Bourdieu, 1998, p.2).

The book, however, also incorporated segments from magazines, pictures, as well as observations captured during involvements in a particular social environment. What is of essence here is that Bourdieu fused all his data; he combined all the different collected elements into a whole so that none of the data was given more significance.

The structure on how to engage with data in this study was designed following Bourdieu’s work. Individuals’ characteristics within a particular field were analyzed as they related to their past & present. I explored how a field connects with other fields. Structures of a particular field were observed and a detailed analysis of all individuals from the perspective of the study participant within a particular field and the various positions they hold was provided. Starting with Bourdieu’s approach on how to explore data in this study, the structure of data analysis was driven by techniques used in visual methodology. Here the understanding is that images and text contextualize each other and are evocative of emotion and experience. The researcher makes meaningful links between different experiences, visual data and other objects.

Using visual methodology means recognizing the interrelationship of objects, texts, images and technologies in researching everyday lives and identities. Without Bourdieu’s work it would not have been fruitful to discover and examine the underlying structures and mechanisms that are so easily overlooked. His principles of construction of social space were essential in exploring

young adult transplant recipients' experience of living with a transplanted heart. It is the work of visual methodologist Pink and Health, however, which enabled me to imply an analytic process of making meaningful links between different experiences, visual data and other objects.

Findings from this study could lead healthcare providers in vastly different directions when implementing new clinical programs. Future research projects need to explore these newly proposed clinical programs that build on current transition programs and foster much needed peer interaction. In order to better understand this process the next step is to incorporate research methods like critical ethnographies that capture routines in these new proposed young adult transplant clinics and the social meaning attached to these. Also, participant observation in these new clinic environments might also offer several benefits over interview-dominated approaches. In particular, young men and women in this study adopted a way of answering questions in a very succinct matter. It was difficult at times to establish a more relaxed dialogue. Being asked questions by someone who appears to be associated with the medical team was potentially similar to being asked question during clinic visits. Hence, participants particular habitus of communicating with a person who might have more power, led to short and to the point responses.

It might also be useful to combine observational techniques with interviews conducted by other young adults who are members from the same field. In the book *The Weight of the World*, Bourdieu (1999) at some point interviewed two young men at the same time. As the interview progressed the two participants started asking each other questions and became more immersed in their own dialogue. Bourdieu used this opportunity to observe and withdrew himself from the interview process, because such interactions are ideal in softening hierarchies in participants' playing field. Additionally, providing participants with cameras so that they capture important

events or scenes, as well as written diaries or body maps might be useful techniques in exploring young peoples live circumstances. Such techniques might be useful in emphasizing young peoples' perspectives and ensuring that their own voices are heard within research.

Criteria for Judging Research Quality

Given the assumptions underlying this realist inquiry that acknowledges a relativist epistemology, it is not possible, nor desirable to assess the quality of this health study with a set of analytic criteria from a positivist tradition (Guba & Lincoln, 2005). Guba and Lincoln (2005) established hallmarks for authenticity, trustworthy, rigorous, qualitative inquiry. The study drew on three sets of those hallmark criteria in order to judge process and outcome of the health inquiry: a) fairness, b) catalytic and tactical authenticity, c) reflexivity (Guba & Lincoln, 2005).

Fairness

The criterion of fairness is thought to be a quality of balance, which entails that various opinions, arguments, and concerns need to be apparent in the text (Guba & Lincoln, 2005). Throughout this study I have included direct quotes from participants in order to represent their narrative of what it is like to live with a transplanted heart. This study provides an empirically grounded description of young adults struggle with relational dispositions and how healthcare providers are holding a dominant position over recipients. By drawing attention to the underlying structures of the healthcare field, it was possible to recognize how particular hierarchies and its practices were taken up and reproduced in the adult transplant clinic. Direct quotes and the language used in this study provide a thick description of what it is like to grow up with a transplanted heart and ultimately transition from a paediatric to an adult healthcare facility.

In order to capture participants' narrative in this health inquiry, all possible efforts were made that each participant was given equal opportunity to tell their story during the interview. Meeting this criterion meant acting in a positive way when including participants in the study. My role as a researcher was to attempt to prevent marginalization, and to act with energy to ensure that all voices, as well as their bodies, in this study had a chance to be represented in the text and to have their stories treated fairly and with balance.

The overall interview approach was guided by Bourdieu's methodological and theoretical focus on life circumstances, activities/practices and the logics that coordinate them. In order to engage study participants in true conversations, Bourdieu asks the interviewer to be aware of the way we look at other people in ordinary circumstances of their lives. The understanding here is that I was reflexive of the effects I might have on the interviewee. This implies that when I interviewed study participants, I had an understanding of what can be said and what should be avoided in order to foster non-violent communication. For Bourdieu non-violent communication means avoidance of symbolic violence, which refers to imposing one's own view on the participants' reality. What was required is the creation of a relationship between myself and the interviewee that is based on active and methodical listening that was achieved by adopting the study participants' way of communicating and adhering to their personal positions and view of the world.

As the study unfolded and I learned more about young adults' struggles with dominant positions within competing fields, I realized that I might also reproduce a particular dominant discourse. As a white male adult working closely with the medical staff, study participants might have thought of me as a member of the healthcare team. This became more apparent to me during the interview process when I asked a particular question; recipients answered it very

politely and waited for me to ask the next question. What had happened was that recipients provided precise answers, just like “a good patient” would, but took little initiative to explore themes outside the asked questions. Also the typical patient is also cognizant that healthcare providers do not want to take too much time in clinical encounters, so shorter answers are expected. Even though I encouraged participants to talk about anything that they felt was important for them, it seemed difficult for them initially to change this deeply ingrained habitus acquired during clinic visits.

What was needed was a return to Bourdieu’s work in order to gain more insights on his interview techniques. In his book ‘The weight of the world’, Bourdieu and his collaborators showcase dozens of interviews with people living in hardship in one form or another, at the extreme margins of society. Bourdieu’s interview style is more representative of a dialogue with questions focusing on: who..., when... and where... in order to better understand participants life circumstances. Hence in the following interviews, I spent more time at the beginning of the interview to make study participants feel comfortable. I demonstrated a more casual demeanour and strongly adhered to their communication style. I also incorporated prompts such as “Who helped you with this and how?”, “When did this occur?”, “Where did you experience this?”, “What else was going on in your life at that time?” in order to further explore particular concerns and adapt a more relaxed conversation style.

Given that the study was informed by the work of Bourdieu, more specifically his conceptualization of how capital is visible in the form of objectification, embodiment and formation of habitus (ones disposition), this study did not privilege speech as the route to explore the participants lived experience. Therefore, during the interview sessions, I was also attuned to participants’ physical comportment, body language, use of personal artefacts (i.e. jewellery,

religious icons), and mannerisms such as sitting position, hand gesture, arm movements, facial expressions, as well as tone of voice, pace of speech, coughs, laughter and pauses. To this end, audio/video observational techniques were used because they are methods that are congruent with Bourdieu's understanding of how capital is formed and manifested. These techniques included the use of unobtrusive digital streaming audio/video camera to record the interview.

Catalytic and tactical authenticity

The catalytic and tactical authenticity criterion involves consideration whether the proposed health inquiry has the potential to lead to action, or creates the capacity in research participants for positive change (Guba and Lincoln, 2005). Meeting this criterion requires a review of the knowledge translation process and how these findings might be incorporated into clinical practice in order to stimulate action. This study captures the lived experience of young adult transplant recipients and their struggles leading to practices of accommodation, “normalization” and withdraw that in turn contribute to perpetuating established relations of exclusion of recipients from various fields. This study, however, also needs to be viewed as an application of Bourdieu's theory. Like other critical approaches it illuminates the logic of practices by reflecting on the embodiment of social order. These social orders are structured by various practices and reproduce relations of domination and exclusion. Hence, exposing (mis)recognitions of normative ways of practices in the clinic that perpetuate symbolic violence and ultimately impacts recipients health.

If possible change is to come out of a particular study and it is not only enough to describe particular events, but also highlight and understand mechanisms by which participants struggle prevail. Findings in this study have potential to significantly improve transplant

recipients lives. Healthcare providers silence might otherwise contribute to young transplant recipients struggle and powerlessness. The medical community needs to acknowledge the findings of this study and educate young adult transplant recipients about the difficulties of living with a transplanted heart. As discussed throughout this thesis, findings are consistent with other researchers work, adding to empirical work for evidence practice.

Results of this study will enhance the understanding of what it is like for young adults, who received a heart transplant in childhood and have ultimately transitioned to an adult healthcare facility. Such findings can potentially lead to improvement in ongoing care and services for young adults who require a lifetime of care. As reported by Harden (2012) there is a need to change clinical practice by initiating a separate young adult transplant clinic, removed from the hospital setting, in order to initialize much needed peer interaction. At the same time, it will allow nurses to better prepare and counsel young individuals who are preparing for a heart transplant, or already live with a transplant. Knowledge translation strategies will include academic presentations, presentations at conferences, journal publications and strategies to communicate with patient groups. The use of visual methodology allows findings to be summarized and presented in the form of short documentaries that may be geared to the interests of clinicians or to those of patients.

Reflexivity

Given my theoretical stance in this research project it is essential to conduct an in-depth analysis of my personal assumptions and intricate relationships with study participants. Reflexivity offers one tool for such an evaluation and is an essential step in Bourdieu's view when study participants are being objectified within a particular field. In most qualitative

research this means self-awareness, as well as a simple awareness of socio-historical context. For Bourdieu, however, reflexivity has a specific character. He argues that it is fundamental to employ the same epistemological approach to the objectifying subject that was used to produce knowledge about a particular object in the first place (Grenfell, 2008). To this end, throughout this research project, I highlighted why this particular study was chosen and what brought it about.

I approached the project as a white male nurse and graduate student, who immigrated to Canada from Austria. Over the last fifteen years, I have gained extensive transplant and cardiology experience working as an advanced practice nurse in a tertiary healthcare facility. More recently, I worked as a research associate, which enabled me to collaborate with a multidisciplinary team on two very innovative qualitative research projects involving adult transplant participants and children with disabilities. My past and present have shaped my own positionality, which orients my way of constructing objects within this study by stressing issues of importance and providing a means of thinking relationally about those issues.

When designing this study I knew from the literature review that healthcare providers had limited evidence on how to best provide care to young adult transplant recipients. As I designed this study, however, I struggled with the idea on how to best conceptualize young adult transplant recipients lives. This was during a time when I first became interested in the work of Bourdieu. I was involved in a research project that examined the process of incorporating a transplanted heart. At that time, I interviewed a 55-year-old transplant recipient who was overcome by feelings of uncertainty and experienced severe symptoms of depression. During this research study, I became aware of the profound interconnectedness of physiological, psychological, social, and cultural facets of an individuals reality. Knowledge gained during this

interview sparked my interest in the interplay between social structure and individual agency in health and illness. Moreover, throughout this project I have provided my own positionality about knowledge production; more specifically during data collection and analysis, I was transparent about how young adult transplant recipients are being constructed within this particular study. Thus, I reflected on the processes of objectification and in doing so objectified myself.

Throughout this study training as a researcher also meant being a graduate student with an interest in an academic research career. Hence, I was also part of particular fields, an educational field or academic field. The academic field, like the healthcare field is composed of members that represent a complex network where power is no longer established by individuals, but through objectification of artifacts that represent power. Diplomas and degrees, for example, are such artifacts that have been established by institutions ensuring a dominant status of a particular group in a specific field. That is the acceptance of socially guaranteed qualifications, and the holding of socially defined positions guarantees members social value of qualifications and the distribution of these values to others. Hence, the kind of capital that is at stake in the academic field is knowledge, which one holds, or demonstrates of having a significant amount of in the form of a PhD. Indeed, I engaged in this research project in order to better understand transplant recipients' experiences, with the hope to provide empirical evidence that would impact the status quo on how care is being provided. But in keeping with Bourdieu, I certainly also did this work in order to accumulate the type of capital that is of value in the academic field, which is the completion of a PhD. To that end, my work is shaped by my affiliations to the clinical as well as the academic field with all its values and symbolic structures, that enabled me to provide theoretically informed accounts of recipients' experiences.

Study Limitations

The major limitations of this study are that although all eligible participants in the adult transplant clinic were approached to participate in this study, one male declined and stated that it is too hard for him to remember and talk about what he has been through. Two female transplant recipients withdrew their consent and stated that it would be too difficult to relive the past.

Another young man declined because he experienced severe symptoms of depression. And one young man struggled with mental disability and had difficulties articulating his thoughts.

Thirteen others declined because they reported that they are too busy with school or work to take part in this study. Others lived too far from the hospital and parents frequently were in a rush to leave the clinic to return back home. What some of these declines might imply is that certain young adult transplant recipients were so disturbed by their transplant experience that the requests to take part in a study made them feel uncomfortable. The thought of talking about their past experiences was so painful for them that they are still struggling with the aftermath that is best concealed and forgotten. In keeping with findings of this study it could also imply that like any young adult transplant recipient they see themselves living “normal” healthy lives. This “normalization” might make it difficult to talk about something that is potentially upsetting and better left in the past. Alternatively, participants also reported that only someone who has been through a similar event could start to begin to understand the hardship of living with a transplanted heart. Thus, the exercise of talking to a researcher about this might seem less fruitful or rewarding for potential participants.

Some participants might find it hard to articulate their experiences or speak to the questions posed. With this limitation in mind, the results of this study should not be interpreted to mean that all young adult transplant recipients have “normalized” their experience and

struggle with relational dispositions. For some there might be deep wounds that have never been captured in this study. Given that this is a qualitative study, I understand that the results may not accurately represent the experiences of all heart transplant patients or recipients of other organs. The assumption is, however, that individuals in similar circumstances might have comparable experiences as highlighted in this study.

Also, UHN is a large teaching hospital that uses global protocols in transplantation, and its patient population is ethnically and socio-economically diverse. I therefore do anticipate that these findings will have relevance for other heart transplant programs.

In conclusion, more and more young adults who have received a paediatric heart transplant are surviving into adulthood and receive ongoing care in an adult healthcare facility, which is an important concept for health care providers. Currently there are transition programs in place in order to help vulnerable patients during this time. This research has identified, however, that additionally what is needed is an approach that acknowledges recipients' struggles with their competing demands from various social environments and fosters peer interaction in order to improve the lives of young adults. This was followed by recommendations to improve current clinical practice, enabling a new and more comprehensive understanding of the young adults complex live circumstances. In the future, based on the recommendations in this study programs should be able to address more comprehensively young adult transplant recipients unique need, making it more likely that individuals who live with chronic illness can achieve their full potential under appropriate medical surveillance and live meaningful and productive lives.

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Appendix A – Ethics Review

University Health Network
Research Ethics Board
10th Floor, Room 1056
700 University Ave
Toronto, Ontario, M5G 1Z5
Phone: (416) 581-7849

Notification of REB Initial Approval

Date: October 6th, 2011

To: Dr. Heather Ross
Rm 1203, 11th Floor, New Clinical Services Building,
Toronto General Hospital,
585 University Avenue
Toronto, Ontario, Canada
M5G 2N2

Re: 11-0587-BE

The Transformed Body: A Bourdieusian Examination of Living into Young Adulthood Being a Pediatric Heart Transplant Recipient

REB Review Type: Expedited
REB Initial Approval Date: October 6th, 2011
REB Expiry Date: October 6th, 2012

Documents Approved:

Protocol	Version date: June, 2011
Consent Form	Version date: September 22nd, 2011
Research Project Summary	Version date: July 25th, 2011
Interview Questions	Version date: September 22nd, 2011
SF-36 Questionnaire	Received on: September 29th, 2011

The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement, ICH Good Clinical Practice Guidelines, Ontario Personal Health Information Protection Act (2004), Part 4 of the Natural Health Product Regulations and Part C, Division 5 of the Food and Drug Regulations of Health Canada.

Best wishes on the successful completion of your project.

Sincerely,

Anna Gagliardi, PhD
Co-Chair, University Health Network Research Ethics Board

University Health Network
Research Ethics Board
10th Floor, Room 1056
700 University Ave
Toronto, Ontario, M5G 1Z5
Phone: (416) 581-7849

Notification of REB Continued Approval

Date: August 21st, 2012
To: Dr. Heather Ross
Rm 1203, 11th Floor, New Clinical Services Building, Toronto General Hospital, 585 University Avenue
Toronto, Ontario
Canada
M5G 2N2
Re: 11-0587-BE
The Transformed Body: A Bourdieusian Examination of Living into Young Adulthood Being a Pediatric Heart Transplant Recipient

REB Review Type:	Expedited
REB Initial Approval Date:	October 6th, 2011
REB Annual Approval Date:	October 6th, 2012
REB Expiry Date:	October 6th, 2013

The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement, ICH Good Clinical Practice Guidelines, Ontario Personal Health Information Protection Act (2004), Part 4 of the Natural Health Product Regulations and Part C, Division 5 of the Food and Drug Regulations of Health Canada.

Best wishes on the successful completion of your project.

Sincerely,

Christopher Zehr, MSc
Research Ethics Coordinator

For: Anna Gagliardi, PhD
Co-Chair, University Health Network Research Ethics Board

Appendix B – Recruitment Package

WELCOME!

This letter is to notify you about an exciting project that we are doing in Transplant. We would like to interview you to learn more about what it was like to switching your care from the Hospital for Sick Children to the University Health Network and the experiences that you've been through.

Enclosed is a package of information. Please read through carefully. One of my research assistants will be contacting you to see if you are interested in being involved.

We want to find out what you think, in order to try to make the transplant process a more successful one.

Sincerely,

Heather Ross, MD, MHSc, FRCPC

University Health Network

Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

Research Project Summary

Thanks again for your interest in this study. We are doing this research to understand what it is like to switch from pediatric health care to an adult health care facility. Doctors, nurses and other members of the health care team need this information in order to give patients the best possible care. We need to know how to fully inform patients before they have the operation and we need to understand patients' needs and concerns after the operation in order to address them.

The study will involve approximately a one and a half hour discussion with a doctoral student who has experience with transplant recipients through his role as an advanced practice nurse.

You will be asked 5-10 open ended questions during the interview, which is expected to take approximately one and a half hours. The interview will be scheduled at your convenience. It will be audio and videotaped with your permission. If you are agreeable we would like to interview you in your home, however, if you wish we will interview you at the hospital in a private room or at another location of your choice.

All information obtained during the study will be kept strictly confidential.

Your participation in this study is voluntary. If you choose not to participate or withdraw from it at any time, your medical care at UHN will not be affected in any way.

If you have any questions, please call the principal investigator for this study Oliver Mauthner at 416 340 4800 Ext. 7362, or Dr. Heather Ross at 416 340-3482.

If you require any follow-up after your interview, please use your Easy Call system at 416-351-0793.

University Health Network

Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

STUDY TITLE: CONSENT TO PARTICIPATE IN A RESEARCH STUDY
The transformed body: A Bourdieusian examination of living into young adulthood being a pediatric heart transplant recipient.

INVESTIGATOR: Oliver Mauthner RN, BScN, MN, PhD(c)
NCSB 11C-G31
585 University Ave
Toronto Ontario
416-340-4800 Ext. 6971

CO-IVESTIGATOR: Jan Angus PhD, MScN, BScN, RN
Denise Gastaldo PhD, MA, BScN;
Heather Ross MD, MHSc, FRCO(C)

24 HOUR PHONE NUMBER: ***Oliver Mauthner 416-340-4800 ext. 7362***

Introduction

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background and Purpose

You have been asked to participate in a study because you have had a pediatric heart transplant and now receive care at the University Health Network. Young adults who have received a pediatric heart transplant have experienced multiple life sustaining procedures. As survival and longevity increase, it has become clear that transplant recipients experience negative physical, emotional and social outcomes. With heart transplant offering individuals a chance to extend life into young adulthood, recipient's need lifelong care and will transition from a pediatric to an adult healthcare facility. Very few studies have been conducted on young adults who have had a

pediatric heart transplant and have switched their care to an adult healthcare facility. We would like to talk to you about what it was like for you to transfer your care to the University Health Network and the circumstances that have impacted your life. Sharing insights from your experience will provide valuable information to healthcare professionals. The better we understand the range of consequences of heart transplantation for patients' lives, the more effective we can address patients' needs and hopefully prepare candidates for all potential outcomes.

Study Design and Procedures

You are being asked to participate in a research study that uses interview techniques to learn more about what it is like to live with a heart transplant. We would like to conduct this interview in your home unless you prefer to be interviewed elsewhere. At the beginning of our meeting you will be asked to complete a short questionnaire that will help the research team to learn more about your physical and emotional wellbeing. After you complete the questionnaire, the study will involve a one-hour discussion with a doctoral student who has experience in peer-to-peer education and counseling through his role as an advanced practice nurse. He will ask you general questions about switching care from one hospital to another, what it is like for you to receive care at the University Health Network, as well as general questions about living with a heart transplant. The discussion will be audio and videotaped with your permission. Short sections of your recorded voice and some photographs from the videotape, that will not reveal who you are, would be shown at scientific meetings and to teach health researchers. The final section of this consent form includes a more detailed explanation about giving or withholding consent for the use of audio (sound) and visual images (photographs).

Risks related to Being in the Study

The risk of this discussion may include bringing forward emotional topics and discussion that you may or may not have thought of recently. Also, the use of sound or photographs from your interview includes the very small possibility that someone who knows you very well could identify you. At no time would identifying information about you be given to anyone. Considering allowing the use of these materials may cause you to feel anxious and/or uncomfortable. If you do find yourself upset by thinking about interview or on the request to use sound and pictures from the interview, Dr. Heather Ross (416-340-3482) would be very pleased to speak with you. In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

Benefits related to Being in the Study

You will not receive any medical benefit from your participation in this part of the study. Communicating information learned from the interview study through the use of voice segments and photographs may benefit other heart transplant patients in the future.

Voluntary Participation

Your participation in this part of the study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your medical care. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying "pass". If you wish to withdraw your consent for the use of recordings or photographs at any time, please call Oliver Mauthner 416-

340-4800 ext. 7362. Recordings or photographs may be used up to the time of withdrawal but no new analysis or presentations will be done on the recordings or photographs after withdrawal.

Compensation

You will not receive any financial reimbursement for allowing the use of recordings or photographs from your interview.

Confidentiality

If you agree to join this study, the study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could be used to identify you and includes your:

- *Name*
- *Address*
- *Date of Birth*
- *New or existing medical records, that includes types, dates and results of medical tests or procedures*

The information that is collected for the study will be kept in a locked and secure area by the study staff for 10 years. Only the study team or the people or groups listed below will be allowed to look at your records. Your participation in this study also may be recorded in your medical record at this hospital.

The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

- *Representatives of the University Health Network Research Ethics Board*

Study Information that Does Not Identify You

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

As you read through the consent form, you will see that the possibility that someone who knows you very well might be able to identify you varies. By working through the choices, you have the opportunity to choose the level of confidentiality with which you are comfortable.

If you decide to leave the study, the information about you that was collected before you left the study will still be used. No new information will be collected without your permission.

Giving or Withholding Consent to Use Audio (Sound) and Visual Images (Photographs)

We are asking you to consider giving consent for the use of brief audio segments (sound including your voice) and visual images (still photos). There are different options for the use of audio and visual images. In some options someone who knows you very well could identify you. Other options would allow the researchers to only use materials that could not be linked to you in any way.

This consent form is broken down into three sections depending upon where the photographs or sounds would be used: scientific meetings, educational events for health care professionals, communicating the results of the study to the public.

I. PRESENTATION AT SCIENTIFIC MEETINGS

Scientific meetings are meetings or conferences where transplantation and other health care researchers learn about findings from new studies.

Please tick which uses of your interview you would be comfortable with at scientific meetings.

I give permission for the use at scientific meetings of the following parts of my videotaped interview without using my name or identifying me:

- ☐ Videotape (both sound and picture) including my face but without using my name
- ☐ Only a part of the videotape (check all parts that you agree to)
 - ☐ Videotape (both sound and picture) without showing my face and without using my name
 - ☐ Photographs (still photos) of my face
 - ☐ Photographs (still or moving photos) of body gestures (e.g. hand movements) without showing my face
 - ☐ Audio (sound of my voice or sounds in the interview room) without any video image/photos
- ☐ I do not give my permission for any use of my videotaped interview at scientific meetings

II. PRESENTATION AT EDUCATIONAL EVENTS

Educational events for health care professionals include events where different health care professionals (e.g. doctors, nurses, researchers) learn about medical conditions or how to do research. .

Please tick which uses of your interview you would be comfortable with at educational events.

I give permission for the use at educational events of the following aspects of my videotaped interview without using my name or identifying me:

- ☐ Videotape (both sound and picture) including my face but without using my name
- ☐ Only a part of the videotape (check all parts that you agree to)
 - ☐ Videotape (both sound and picture) without showing my face and without using my name
 - ☐ Photographs (still photos) of my face
 - ☐ Photographs (still or moving photos) of body gestures (e.g. hand movements) without showing my face
 - ☐ Audio (sound of my voice or sounds in the interview room) without any video image/photos
- ☐ I do not give my permission for any use of my videotaped interview at educational events

III. COMMUNICATING THE RESULTS OF THIS STUDY TO THE PUBLIC.

We are interested in developing a short documentary that would help to convey to patients, families and the general public, what it is like to live with a heart transplant.

Please tick which uses of your interview you would be comfortable with in being used for the production of a documentary about young adults living with heart transplantation.

I give permission for the production of a documentary of the following parts of my videotaped interview without using my name or identifying me:

- ☐ Videotape (both sound and picture) including my face but without using my name
- ☐ Only a part of the videotape (check all parts that you agree to)
 - ☐ Videotape (both sound and picture) without showing my face and without using my name
 - ☐ Photographs (still photos) of my face
 - ☐ Photographs (still or moving photos) of body gestures (e.g. hand movements) without showing my face
 - ☐ Audio (sound of my voice or sounds in the interview room) without any video image/photos
- ☐ I do not give my permission for any use of my videotaped interview at scientific meetings

In Case You are Harmed in the Study

If you become ill, injured or harmed as a result of taking part in this study, you will receive care. The reasonable costs of such care will be covered for any injury, illness or harm that is directly a result of being in this study. In no way does signing this consent form waive you legal rights nor does it relieve the instigators, sponsors or involved institutions from their legal and professional responsibilities. You do not give up any legal rights by signing this consent form.

You will not have to pay for any of the procedures involved with this study. You will not be reimbursed for time, inconvenience etc.

Questions About the Study

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Oliver Mauthner 416-340-4800 ext. 7362

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (REB) or the Research Ethics office number at (416) 581-7849. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

Consent

This study has been explained to me and any questions have been answered. I know that I may leave the study at any time. I agree to take part in this study.

Print Study Subject's Name

Signature

Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study the participant named above. I have answered all questions.

Print Name of Person

Signature

Date

Obtaining Consent

Appendix C – Interview Questions

The overall interview approach is guided by Bourdieu's methodological and theoretical focus on life circumstances, activities/practices and the logics that coordinate them. In order to engage study participants in true conversations, Bourdieu asks the interviewer to be aware of the way we look at other people in ordinary circumstances of their lives. The understanding here is that I will be reflexive of the effects I might have on the interviewee. This implies that when I interview study participants, I have an understanding of what can be said and what should be avoided in order to foster non-violent communication. For Bourdieu non-violent communication means avoidance of symbolic violence, which refers to imposing one's own view on the participants' reality. What is required is the creation of a relationship between myself and the interviewee that is based on active and methodical listening that is achieved by adopting the study participants' way of communicating and adhering to their personal positions and view of the world.

In his book 'The weight of the world', Bourdieu and his collaborators showcase dozens of interviews with people living in hardship in one from another, at the extreme margins of society. Bourdieu's interview style is more representative of a dialogue with questions focusing on: who..., when... and where... in order to better understand participants life circumstances. Hence, I will be using prompts such as "Who helped you with this and how?", "When did this occur", "Where did you experience this?", "What else was going on in your life at that time?"

Given that the study is informed by the work of Bourdieu, more specifically his conceptualization of how capital (various forms of cultural exchanges) is visible in the form of objectification, embodiment and formation of habitus (ones disposition), this study will not privilege speech as the route to explore the participants lived experience. Therefore, during the interview sessions, I will also attend to participants' physical comportment, body language, use of personal artifacts (i.e. jewelry, religious icons), and mannerisms such as sitting position, hand gesture, arm movements, facial expressions, as well as tone of voice, pace of speech, coughs, laughter and pauses. To this end, audio/video observational techniques will be used because they are methods that are congruent with Bourdieu's understanding on how capital is formed and manifested. These techniques include the use of unobtrusive digital streaming audio/video camera to record the interview.

Introduction of the interview

I will begin the formal session using a standardized introduction:

Thank you for agreeing to be interviewed for this study. As we discussed earlier, I am doing this research to understand what it is like to make the switch from receiving care at HSC to UHN and your experience as a young adult living with a heart transplant. It is important to better understand the experience in order to better address transplant recipients needs and concerns. Our conversation will be video and audiotape recorded so I will be able to review the whole interview at a later time.

Before we start, I want to remind you about a few things:

- Everything you tell me will be kept strictly confidential.
- You may refuse to answer any of my questions for any reason at all.
- I realize this may be very emotional, for you and possibly for me too, so if you need to take a break, get support, or just need to cry... that's fine.
- If you like me to erase anything you have said from the tape, please let me know.
- Please don't hesitate to tell me if you would like to stop the interview at any point in time

Do you have any questions or comments before we begin?

Getting to know the participant

I have some questions to help us get started but I hope you will feel free to talk about things I may not ask. Everything you think I should know about your experience is important.

1. How old were you when you had your transplant?
2. What else was going on in your life at that time?
3. Could you tell me a bit more about your life now?

Prompts: main activities, self care routines such as medication, meals, leisure, usual people they come into contact with, etc.

Making the switch

We are here today because at some point you had to make the switch from pediatric health care to adult health care.

4. Could you tell me what you remember about moving from HSC to UHN?
5. How were you prepared for your transfer?

Prompts: Were you part of a transition program, how was information given to prepare you, who were the people you were in contact with, when did the switch occur, what was helpful/not helpful during that time, etc.

6. What else was going on in your life when your care was transferred to UHN?

Receiving care at UHN

Living with a chronic disease entails that transplant recipients' healthcare needs change and individuals constantly need to adjust to their disease sequelae.

7. What is it like being a transplant patient at the University Health Network? What is a typical clinic visit like for you?
8. How is being a transplant patient at UHN different/or not different from Sick Kids Hospital?
9. What is it like working with your main health team members?
10. Who understands best what you are going through as a heart transplant recipient? Tell me about their involvement in your health....
11. How involved/not involved is your family in your care? Who made this arrangement and would you like to change anything about your family's involvement in your care?

Life as a transplant recipient in general

Young adults who have received a pediatric heart transplant have experienced multiple life sustaining procedures. Very little health research exists that highlight the experience and challenges of young adults living with a transplanted heart.

12. How do you feel about yourself as a heart transplant recipient?
13. Do you talk about your transplant with other people?
14. Tell me a little about your friends? What do you like to do together?
15. Please tell me about your living arrangements.... If not, who do you live with?
16. I have one last question; please tell me what this interview was like for you?

Appendix D – Time Intervals

	Months 1-3	Months 4-7	Months 8-11	Months 12-15	Months 16-19
Received ethics approval	X				
Recruited participants	X	X			
Interviewed participants	X	X			
Transcribed & organized data using NVivo 9	X	X	X		
Analysed data	X	X	X	X	
Wrote up findings				X	X