THE RENAL TRANSPLANT EXPERIENCE

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PATIENTS' POST-OPERATIVE PERSPECTIVES AND THE SOCIAL WORK ROLE

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Abstract

This qualitative study examines the experiences of patients who have undergone renal transplant surgery. Interviews were conducted with six patient informants who received renal transplants one to six months prior to the study. Participants' narratives offered insight into: the variability of transplant preparation, hopes, experiences, and perspectives of recovery, meanings of recovery, significance of social and economic supports in recovery, and the role of professional staff in providing support and resources during the transplant journey. Their stories are explored in relation to literature on psychosocial aspects of renal transplant and through a critical disability studies lens. The nuances of the social work role in relation to patients' pre- and post-operative renal transplant journey was explored in depth. Based on the findings and relevant literature, recommendations and suggestions are made on how to expand the social work role in the pre- and post-transplant clinic at St. Joseph's Healthcare Hamilton.

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Chapter One: Introduction

Receiving a renal transplant is a very exciting opportunity for individuals living with end-stage renal disease. It allows the opportunity to live a life free of dialysis. There are over 100 completed renal transplants at St. Joseph's Healthcare Hamilton (SJHH) each year involving donations from both live and deceased donors. Patients travel to SJHH from various cities within the catchment area including Hamilton, Niagara, Haldimand, and Brant for their pre-transplant appointments. These appointments include various diagnostic tests, surgical assessments, and their social work assessment (to name a few mandatory pre-operative consultations).

The entire work-up for patients receiving a transplant from a deceased donor (as was the case for all participants in this study) can range from several months to years. Once they have been deemed eligible and placed on the waiting list, the time to transplant may be quite short if the person has already been on dialysis for several years, or considerably longer if they have not. These varying time trajectories have a significant effect on how patients prepare themselves.

Currently, the social work role with people who are planning for transplant is limited to one single consultation. The social worker assesses the various psychosocial domains including: current living situation, general medical information, income source, medication coverage, decision to pursue a transplant, social supports, mental health history, substance use history, coping skills, transplant medication understanding and adherence to treatment, and potential challenges (Sas, 2019). Once the consultation is complete, a report is written and attached to the patient chart for physician review. If there are concerns identified, such as lack of transportation, untreated mental health diagnoses, or minimal social supports, it is outlined within the report. The patient is then referred back to the primary social worker providing services within their home hospital or dialysis centre for follow-up. Importantly, the time between the social work assessment at SJHH and transplantation could be several years. There is limited consultation between the SJHH and the primary social worker over this time.

The limitations of the pre-transplant social work role at SJHH are thus significant. Social concerns identified at the initial SJHH consult as relevant to transplant preparation and recovery might have gone unaddressed. New social concerns might have emerged and no additional assessment is done, even if the transplant is happening years after the initial assessment. Patients called in for deceased donor renal transplantation may present to the hospital unprepared or unaware of what their post-operative course may look like in terms of follow-up appointments and their care regimen. Many times, even if this information has been provided, it is forgotten by patients due to the overwhelming nature of the process and perhaps the distant social work appointment that occurred in the years preceding surgery.

It is important to acknowledge that many transplant centres across Ontario require patients to have certain kinds of supports including proof of medication coverage, prior to transplantation. SJHH does not have these requirements. Although SJHH policy is inclusive of everyone regardless of socioeconomic status and social supports, it can place patients at a disadvantage to receive a transplant when they do not have the necessary means, such as medication coverage, to be able to care for themselves and their new organ post-operatively. These situations can lead to patients not taking their mandatory immunosuppression medication, placing them at high-risk for organ rejection.

For many years, clinic staff including transplant coordinators and transplant nephrologists, have been suggesting an expansion of the pre-transplant social work role at SJHH. The purpose of my study was to understand, from the perspective of post-operative transplant recipients, the supports needed in a transplant journey. My goal was to use the findings of this study to recommend ways to enhance the social work role in renal care.

Preliminary review of the research revealed the importance of addressing mental health conditions of transplant candidates. Kuntz and Bonfiglio (2011) discuss the importance of diagnosing and treating psychological disorders prior to transplant surgery as they identify a link between successful transplantation and treated mental health conditions. Lamba et al. (2012) report that untreated mental health or addictions issues may put individuals at higher risk for post-operative treatment non-adherence, which could be addressed by enhanced social work intervention pre-transplant. Kumnig and Jowsey-Gregoire (2015) suggest a multi-disciplinary and multi-staged approach to pre-transplant care that identifies suitable transplant candidates, indicating that social work interventions yield improved outcomes.

New and innovative methods for pre-transplant evaluation were discovered. De Geest et al. (2013) discussed the Swiss Transplant Cohort Study's biopsychosocial framework and argued that this approach to transplant care (rather than the standard biomedical model) is crucial in order to propel the field forward. De Geest et al. (2013)

hypothesize that lack of improvement of long-term survival rates of transplant recipients is related to psychosocial and behavioural factors.

For this thesis, I was interested in understanding the complexity of the pre-transplant patient experience and how patients perceive their feelings of preparedness. I was also interested in hearing patient recommendations to future transplant recipients and clinic staff with regards to pre-operative education. Although there is research implying that pre-operative attention to psychosocial factors positively impacts the transplant outcome, I have come across few qualitative studies that were conducted through the patient lens using the interview method. Tong, Chapman, Israni, Gordon, and Craig (2013) suggests interviews are useful in gaining insight into individuals' experiences, values, and attitudes in order to inform healthcare practice and policy. Qualitative research provides insight that is informing to clinical practice and policy, potentially improving transplant outcomes (Tong et al., 2013).

My research goals included: to learn about participants' perspectives about preparation for renal transplant surgery including their fears and worries; to understand what information is most valuable to participants in terms of pre-transplant education; and to obtain recommendations from participants to transplant clinic staff and future transplant recipients on preparing for surgery/recovery. Because my preliminary literature review strongly suggested the benefits of pre-operative social work intervention, I hope that my research study will positively impact the social work complement within the transplant clinic at SJHH.

Chapter Two: Literature Review

The opportunity of a renal transplant – receiving a kidney from a live or deceased donor – offers people with end-stage renal disease the chance to live a life free of dialysis and improved health. It is thus typically very welcomed by patients and their families. At the same time, preparing for and recovering from a transplant can be demanding in a range of ways. For this thesis, I explored the social science and health science literature for qualitative interviews relating to individuals who have renal disease and either received dialysis, a transplant, or both. My review of the literature is organized into the following themes: living with end-stage renal disease, psychosocial wellbeing pre- and post-transplant, social supports (and lack of social supports) for people facing renal transplant, socioeconomic contexts of end-stage renal disease, and post-transplant quality of life. Included in my review are results of a small research literature about social work support for individual with end-stage renal disease/individuals undergoing transplant.

While I made specific efforts to gather social science literature about living with renal disease, most of the literature I was able to find adopts a biomedical framework and focuses on individual patients, with limited attention to the social, political and economic contexts of their lives and their care. Although it offers some entry ways for social work, especially related to patients’ psychosocial wellbeing, critical social science and critical disability studies analyses are lacking and needed in this field. I take up this point again in the Discussion chapter.

Living with End-Stage Renal Disease

For most individuals, end-stage renal disease is a daunting diagnosis to receive. Although there are various treatment options, it is important to note their effects and overall impact on individuals living with the disease. Welch (1994) states there are three treatment options for end-stage renal disease: hemodialysis, peritoneal dialysis, and renal transplantation; however, none of these treatments are curative (as cited in Fallon, Gould, & Wainwright, 1997). Welch (1994) suggests these treatments provide symptom relief and extend life-expectancy with the intent to enhance quality of life (as cited in Fallon et al., 1997).

The meaning of illness appears to vary amongst individuals. Caress, Luker, and Owens (2001) argue that meaning of illness for renal disease is under-explored compared to the cancer field, even though end-stage renal disease is chronic with high-demand treatments. Caress et al. (2001) aimed to explore the meaning of illness in a sample of renal patients utilizing Lipowski's (1970) meaning of illness schema highlighting eight categories: illness as challenge, illness as value, illness as enemy, illness as punishment, illness as strategy, illness as weakness, illness as relief, and illness as irreparable. Their study found that the categories were generally applicable to renal disease and that participants mostly selected "challenge" as the way they viewed their illness (Caress et al., 2001).

It is helpful to learn about the meaning of illness directly from individuals living with medical diagnoses. Richards (2008) argues, "the expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability or illness" (p. 1717). Richards (2008) writes from an auto-ethnographical perspective, highlighting her experiences living with end-stage renal disease. She acknowledges the disability movement and the way that individuals living with illness or disability are “othered,” meaning turned into an object (Richards, 2008). Richards (2008) argues that people living with disabilities or illnesses are placed into a medicalized narrative and seen as objects rather than agents. This leads to dehumanization as they are not often asked to contribute to research, therefore being generalized into categories rather than have their unique circumstances emphasized (Richards, 2008). From her perspective, kidney failure and transplantation are under-researched from a qualitative research standpoint (Richards, 2008).

Many individuals develop an outlook focused on the end goal of receiving a transplant, targeting their ambitions around this treatment option. O’Neal (2007) describes the process of normalization as an approach to coping with chronic illness as it, “turns the lens upon the patient and emphasizes their individual efforts and agency in living with their illness” (as cited in Boaz & Morgan, 2014, p. 248). One participant in Boaz and Morgan’s (2014) study described feelings of endless exhaustion and placing her life on hold prior to transplant. Only one participant felt as though he was living a life close to normal as he was able to work long hours and maintain a busy lifestyle (Boaz & Morgan, 2014).

Transplantation and perception of post-operative wellness is a facet of the treatment that has been widely researched from a medical perspective. Boaz and Morgan (2014) argue that transplantation is presented as a cure in popular discourse but that there is minimal literature exploring the patients’ wellness perception after surgery. It is argued that transplantation changes the lives of each individual who experiences the process (Van Der Mei et al., 2007). Individuals must agree to a specific medication regimen and attend various follow-up appointments at the hospital post-discharge (Van Der Mei et al., 2007). In the study of Boaz and Morgan (2014), participants who were three months post-transplant spent time describing the side-effects of immunosuppression including hair loss, weight gain, tremors, sickness, diarrhea, vivid dreams, mood changes, and acne (Boaz & Morgan, 2014). One individual from Boaz and Morgan's (2014) study developed a post-operative diabetes condition causing further interference with his lifestyle compared to receiving dialysis prior to transplant. Transplant rejection is also a possibility, leading patients to feel anxious and fearful of this outcome (Caress et al., 2001). Kerr, Souliere, and Bell (2018) describe ambiguity, paradox, and contrast as the foundation of the existence of individuals with renal transplants. However, despite these challenges, participants in this study took comfort in knowing that these side effects were part of the transplant and the key to recovery (Boaz & Morgan, 2014).

Individuals living with renal disease have discussed their coping strategies in relation to their post-transplant condition. Furthermore, in the study of Boaz and Morgan (2014), a small group of individuals described their focus on "keeping going" as a means to reconcile that transplant is not a cure. For those living with end-stage renal disease, the preferred treatment modality is transplantation, due to better quality of life (White & Gallagher, 2010; Been-Dahmen et al., 2018). Many individuals find relief when their lives no longer involve an endless schedule of dialysis treatments and knowing their life expectancy has increased. Although complications often arise, the majority of individuals will choose transplantation over lifelong dialysis.

Psychosocial Wellbeing Pre- and Post-Transplant

Renal transplantation brings much promise for those living with end-stage renal disease, however, there is also a great deal of anxiety and strain which must be attended to. Amerena and Wallace (2009) emphasize the importance of focusing on psychological issues relating to renal transplantation as there is little published on this topic and because prior transplant studies have indicated anxiety and negative affect are experienced pre- and post-transplant. Olbrisch et al. (2002) suggest pre-transplant individuals experience concerns over psychological evaluation for transplant with the potential for deselection, which in turn may lead to neglecting to express dissatisfaction about the process (as cited in Amerena & Wallace, 2009). Kuntz and Bonfiglio's (2011) study identified that upon initial presentation to a transplant centre, 15.1% of the participants endorsed symptoms consistent with a depressive disorder and 7.6% endorsed an anxiety disorder. Individuals often anticipate the potential for mortality or worsened morbidity along with the potential viability of the donor kidney and side-effects of immunosuppression (Amerena & Wallace, 2009). Nickels (2001) suggests that fear and sadness pre-transplant are associated with decreased post-transplant adaptation (as cited in Amerena & Wallace, 2009).

Research has been done on the importance of control in the context of renal disease and dialysis, as well as transplant. Curtin, Mapes, Petillo, and Oberley (2002) describe the concept of self-efficacy and control. The ability to control as many aspects of one's life as possible is found to be important with regards to adjustment to living with chronic disease (Curtin et al., 2002). Many individuals describe feelings of constant struggle in relation to maintaining control over their health care in addition to everyday life (Curtin et al., 2002). Bandura (1997) suggested, "individuals' belief that they can motivate themselves and regulate their own behaviour plays a crucial role in whether they will pursue rehabilitative activities" (as cited in Curtin et al., 2002, p. 617), demonstrating the benefits of one's ability to feel in control.

There appears to be a correlation between being on dialysis – and the lack of control this involves – and low mood. Schulz et al. (2017) argue, "low levels of perceived control among dialysis patients are associated with increased psychological distress" (p. 1713). Hutchinson (2005) states that between one-third and one-half of dialysis patients have moderate or serious depression. Alternatively, Schulz et al. (2017) state that levels of perceived control increase after kidney transplantation resulting in a reduction of psychological distress, however, this proved to be true for a small number of patients. Freedom from dialysis and post-secondary education are hypothesized to be associated with increased perception of control and therefore lower levels of psychological distress among people who have received a transplant (Schulz et al., 2017).

Individuals on dialysis have adopted their own coping mechanisms. Searching for control is also viewed as a coping strategy in relation to one's health circumstances (King, Carroll, Newton, & Dornan, 2002). Individuals with renal disease often view control over their illness as a means to cope with their diagnosis and attempt to slow down the progression through strict adherence to dietary and treatment regimens (King et al., 2002). On the other hand, some individuals accept the risks associated with transplantation for the possibility of increased independence (and control) rather than living life on a strict regimen of dialysis treatments.

Researchers have identified a number of post-transplant psychological challenges including long-lasting fear of organ rejection (Amerena & Wallace, 2009). Kieran and Maynooth's (2001) study participants demonstrated psychological difficulty adjusting to the side effects of immunosuppression including weight gain and susceptibility to infection. Olbrisch et al. (2002) and Nickels (2001) describe the transplant experience as a trauma, suggesting the onset of post-traumatic stress disorder amongst recipients (as cited in Amerena & Wallace, 2009). Olbrisch et al. (2002) and Nickels (2001) go on to identify major depression, panic disorder, and generalized anxiety disorder post-transplant (as cited in Amerena & Wallace, 2009). Over the long-term, some patients end up not attending their medical follow-up appointments in order to reduce stress (Pascazio et al., 2010). Immunosuppression medications including tacrolimus and cyclosporine can increase the risk of mood disorders (Pascazio et al., 2010). It is also suggested that individuals who are divorced, have a history of alcohol or substance abuse, and those with mental health needs are at greater risk for non-adherence to follow-up treatment (Lamba et al., 2012). Chen et al. (2014) argue that depressive symptoms post-transplant were determined to be an important predictor of social functioning. They suggest that healthcare practitioners must understand transplant recipients' physical and psychosocial problems (Chen et al., 2014). These authors advise healthcare practitioners to develop an evidence-based program for health promotion of renal transplant recipients post-transplant with a specific focus on stress management (Chen et al., 2014). Psychological impacts of transplantation are significant and need attention particularly as they impact recovery in complicated ways.

Although transplantation is a treatment for end-stage renal disease that leads to better overall health when compared to dialysis, individuals often experience transplant failure and may end up requiring more than one transplant throughout the course of their lifetime. The experience of having a failed transplant also impacts one's psychological functioning. Christensen, Holman, Turner, and Slaughter (1989) suggest that patients receiving hemodialysis who have experienced renal transplant failure report significantly more depressive feelings than dialysis patients who have not had a transplant or than successfully transplanted patients (as cited in Ouellette, Achille, & Paquet, 2009). McGee and Bradley (1994) compare this state of depression to the one experienced by individuals after attempting suicide (as cited in Ouellette et al., 2009). Ouellette et al. (2009) describe the concept of suffering in relation to individuals living with end-stage renal disease and that dialysis is often experienced as a burden. Individuals experiencing transplant graft failure often feel shocked and feel like their world has collapsed (Ouellette et al., 2009). These individuals expressed feelings of anger, frustration, sadness, boredom, anxiety, and in more severe cases, thoughts of suicide (Ouellette et al., 2009). Engaging in spontaneous meaning making discussion that aimed at constructing meaning of the transplant failure experience allowed individuals to transition into the acceptance phase (Ouellette et al., 2009).

Poor transplant outcome and pre-operative psychological functioning appear to be connected. De Geest et al. (2013) suggest there is increasing evidence that demonstrates selected psychological factors are independent risk factors for poor transplant outcome. They argue moving from a biomedical model to a biopsychosocial model is crucial in advancing the field forward (De Geest et al., 2013). The goal of the study by De Geest and colleagues was to discuss the Swiss Transplant Cohort Study's (STCS) biopsychosocial framework that forms the basis of psychosocial data collection and measurement (De Geest et al., 2013). They categorize relevant factors that are valuable to be included in psychosocial data collection due to their predictive value for outcome (De Geest et al., 2013). The STCS was inspired by the perspective of Dew et al. (2000) to describe transplant psychosocial domains and outcomes (as cited in De Geest et al., 2013). This prior model included five domains: physical/functional, psychological, behavioural, social, and global quality of life (De Geest et al., 2013).

Long-term survival rates of individuals who have had a liver transplant demonstrates a connection to psychosocial and behavioural challenges. De Geest et al. (2013) adaped this model by adding a timeline that represents the transplant journey, integrating a systems perspective, and suggesting the possibility of interaction amongst the domains. These authors argue it can be hypothesized that the lack of improvement of long-term survival rate of transplant recipients is related to psychosocial and behavioural issues (De Geest et al., 2013). The evidence continues to grow, indicating specific psychosocial, behavioural, and system factors play a part in the determination of clinical outcome in chronically ill patients; including transplant recipients (De Geest et al., 2013).

De Geest and colleagues (2013) conclude by stating the STCS framework has the potential to identify pathways to target transplant outcome improvements in the future. The research of De Geest et al. (2013) is helpful to my study with regards to developing the connection between the social work role and patient preparation for renal transplantation.

Social Supports (and Lack of Social Supports) for People Facing Renal Transplant

Social supports play an integral role in patients coping with and managing their illnesses. The necessary level and kind of social support varies amongst each patient. Research has established a fluctuating level of support specifically related to the patient's medical status. Been-Dahmen et al.'s (2018) study reveals the more complications, the greater the need for support. Conversely, the need for support decreases as post-operative time increases (Been-Dahmen et al., 2018). There are various levels of support including instrumental, relational, and psychosocial (Been-Dahmen et al., 2018). Relational support was identified as valuable by transplant recipients, including having care practitioners who demonstrated empathy, reliability, and listening skills (Been-Dahmen et al., 2018). Participants also identified having care practitioners frequently inquire about their emotional status as being beneficial (Been-Dahmen et al., 2018).

Social supports play an important role in self-management. Audulv, Asplund, and Norbergh (2012) define self-management as, "the strategies individuals undertake to promote health (e.g., healthy living, exercising), manage an illness (e.g., manage symptoms, medication, and lifestyle changes), and manage life with an illness (e.g., adapt leisure activities or deal with losses caused by illness)" (p. 332). Patients often receive support through friends and family, along with health care practitioners (Audulv et al., 2012). Motivation is a key role that social supports can play in chronic disease self-management (Audulv et al., 2012). Social supports can also take part in instrumental tasks such as meal preparation and encouragement to adhere to a particular diet (Audulv et al., 2012). Post-transplant, family members and friends are fundamental with regards to self-management routines. Transportation to appointments and medication reminders are two key areas where having social supports are highly beneficial. Jamieson et al. (2016) state, "multi-component interventions that include education, psychosocial support, decision aids, and pragmatic tools to aid self-monitoring and adherence may improve transplantation outcomes by promoting capacities for self-management and adherence" (p. 475).

It appears that from a psychosocial persepctive, patients can prepare themselves for organ transplantation by further encouraging family support or community resource involvement to secure a strong social network prior to surgery. White and Gallagher's (2010) study reveals married transplant recipients achieve higher quality of life scores in the social relationships domain of their study, indicating increased satisfaction in personal relationships, social support, and sexual activity. White and Gallagher (2010) conclude that having the ability to return to work and a strong social support network are important factors to consider when implementing interventions to maximize post-transplant quality of life. Chen et al. (2014) emphasize the importance of family involvement of the healthcare regimen as Taiwain culture differs from Western culture in this regard.

Socioeconomic Contexts of End-Stage Renal Disease

As I have noted above, many researchers and health professionals emphasize "self-management" for people with chronic illness. Yet patient self-management has also been highly scrutinized. Dillaway and Byrnes (2009) along with Lawn, McMillan, and Pulvirenti (2011) discuss how self-management has been critiqued for not acknowledging various social factors that impact and possibly prohibit individuals from engaging in self-management including poverty and lack of access to health care, placing the responsibility for health on individuals and their choices (as cited in Been-Dahmen et al., 2018). Wilkinson and Kitzinger (2000) along with Broom and Whittaker (2004) explore the moral dimension of self-management, discussing how patients may be blamed or blame themselves for their illness and for not demonstrating a positive attitude, or for making poor lifestyle choices such as neglecting the appropriate diet or exercise (as cited in Been-Dahmen et al., 2018).

Although transplantation is highly sought after by individuals living with end-stage renal disease, the impacts on their lives often goes unknown until they are faced with the post-transplant realities. Pre-transplant patients often demonstrate feelings of uncertainty surrounding the financial consequences of obtaining a renal transplant including costs associated with medication, surgery itself, and post-transplant costs (Martin, Stone, Scott, & Brashers, 2010). Amerena and Wallace (2009) emphasize that the reality of renal transplantation is not often recognized. Kierans and Maynooth (2001) state, "individuals live a life of compromise influenced by uncertain health and immunosuppression" (as cited in Amerena & Wallace, 2009, p. 273). Many people realized that taking care of their families by obtaining a job and contributing as a working member of society was not easy to attain (Crowley-Matowka, 2005). Frequent medical appointments and occasional hospitalizations interfere with their desirability to employers (Crowley-Matowka, 2005). Transplant recipients are often excluded from certain lines of work including labourer jobs such as factory work, machine shops, and agricultural settings due to chemical exposures (Crowley-Matowka, 2005).

Post-Transplant Quality of Life

Quality of life is something that all individuals, whether healthy or unwell, strive to achieve. Although no one particular definition of quality of life has been contrived, the findings of Teeling-Smith (1990), Fallowfield (1990), and Bowling (1991) indicate that quality of life encompasses, "physical health and the experience of distressing symptoms, functional status and the activities of daily living, social function and social support, and psychological well-being" (as cited in Fallon et al., 1997, p. 563). Individuals who have received successful transplants feel less fatigued and less tied down, enhancing their quality of life (Fallon et al., 1997). White et al. (1990) concluded that transplantation does not eradicate stress related to health issues and often individuals who experience the greatest level of stress exhibit the lowest quality of life (as cited in Fallon et al., 1997). Fallon et al. (1997) argue there is research supporting a connection between the stressors of renal transplantation and individuals' health-related quality of life.

There has been a demonstrated connection between quality of life and coping mechanisms. White and Gallagher (2010) indicate quality of life is not a consistently positive experience in relation to renal transplantation, rather, that individual difference factors that influence quality of life including psychological variables must be taken into consideration. They identify a connection between coping mechanisms and quality of life post-renal transplantation including individuals who utilize avoidance by means of distraction had poorer quality of life, when compared to individuals who used more social support-based coping mechanisms (White & Gallagher, 2010).

Social Work Role

The literature suggests the relevance of social work intervention and also calls for more research in this area. Patients and their caregivers experience a high level of stress along the journey. Amerena and Wallace (2009) suggest psychological counselling by supporting patients to accommodate uncertainty, negotiate risk-reducing compromises, and develop positive relationships with self, others, and the new organ. Engle's (2001) study focuses on the effects of end-stage disease on the psychosocial experience of the patient. He discusses the concept of post-transplant underreporting of distress as patients may feel the needs to report a high quality of life to the transplant team due to gratitude they have for their help and ongoing care in the future (Engle, 2001). Engle (2001) reviews various domains of the psychosocial experience including employment, sexual dysfunction, and medication side effects. He identifies gaps in research including the lack of evidence demonstrating support, educational, and psychoeducational groups are effective suggesting we cannot presume these interventions are working (Engle, 2001). He encourages further attention on sexual function in order for patients and spouses to be better served (Engle, 2001). Lastly, he argues there is evidence suggesting caregivers of transplant candidates and recipients are at risk of high stress rates (Engle, 2001). He encourages further studies into interventions that will help serve the population of caregivers, that often goes unnoticed (Engle, 2001).

Social workers are involved in the lives of transplant patients in a variety of ways including coordination of resources to enhance psychosocial support. Flamme, Terry, and Helft's (2008) study with liver transplant recipients aims to improve overall post-transplant outcomes and helping patients attain improved post-operative quality of life. This particular study is helpful because they also identify areas of psychosocial need requiring intervention before and after transplantation (Flamme et al., 2008). They argue longer post-operative survival rates are associated with increased social support and increased medical adherence (Flamme et al., 2008). Furthermore, they argue psychosocial assessment can identify patients who would benefit from enhanced pre-operative psychosocial support or who may be at risk for psychiatric morbidity post-transplant (Flamme et al., 2008).

The interprofessional team assessing individuals for transplantation has a variety of lenses unique to each discipline. Flamme and colleagues' study compares and contrasts the value placed on psychosocial factors involved with liver transplantation between transplant psychosocial evaluators (often social workers) versus transplant surgeons (Flamme et al., 2008). They found that psychosocial evaluators were significantly less likely to recommend an individual with a history of poor social support to be listed for liver transplant than transplant surgeons (Flamme et al., 2008). Flamme and colleagues hypothesize transplant psychosocial evaluators who assess patients pre-operatively but who also follow patients post-operatively may observe that lack of social support can lead to adverse transplant outcomes (Flamme et al., 2008). Flamme et al. (2008) suggest the relationship between available resources such as transportation and adaptatation to stress in relation to transplant outcomes should be further explored.

There appears to be a correlation between successful treatment of psychological condition pre-transplant and overall post-transplant psychological functioning. Kuntz and Bonfiglio (2011) conclude that it is important to examine the mental health prevalence rates throughout various stages and at various conditions during the transplant evaluation process. They make the connection between transplant success and effectively treating psychological disorders pre-emptively by means of cognitive-behavioural group therapy to treat depression amongst patients receiving hemodialysis (Kuntz & Bonfiglio, 2011). This article is pertinent because it raises an important issue with regards to the mental status of individuals undergoing transplantation evaluation and suggests a potentially important social work role.

Psychological assessment is an integral part of pre-transplant evaluation. Determining one's psychological condition pre-operatively can aid in determining a post-operative treatment plan suited to meet one's needs. Kumnig and Jowsey-Gregoire (2015) provide an overview of recent clinical practices, research, and consensus opinion in various types of organ transplantation amongst the domains of evaluation, pre- and post-transplant follow-up, psychiatric complications, evaluation of body image, and health-related quality of life (HRQOL). They argue that patients with personality disorders require close psychiatric pre-transplant evaluation and post-transplant follow-up because they may experience an exacerbation post-transplant (Kumnig & Jowsey-Gregoire, 2015).

They encourage clinicians to engage patients in self-monitoring for psychiatric symptoms in order to advocate for early psychological intervention (Kumnig & Jowsey-Gregoire, 2015). Kumnig and Jowsey-Gregoire (2015) suggest a pro-active approach in supporting patients in their body image, especially if there are pre-transplant issues identified with regards to this. They argue that special attention should be paid to the cognitive abilities of each patient in order to tailor their pre- and post-transplant protocols to meet their needs (Kumnig & Jowsey-Gregoire, 2015). They emphasize the importance of patients' understanding of the treatment, limitations, and possibilities, especially since the pre-transplant process is very long and in depth and can span across a period of years (Kumnig & Jowsey-Gregoire, 2015).

Literature demonstrates a need for a standardized pre-transplant psychological evaluation. Kumnig and Jowsey-Gregoire (2015) indicate that most studies have exemplified the importance of choosing treatment modality based on a wide variety of criteria including psychosocial aspects. They suggest future studies focusing on a standardized protocol in the field of psychological evaluation in transplant medicine (Kumnig & Jowsey-Gregoire, 2015). Kumnig and Jowsey-Gregoire (2015) conclude that successful transplantation incorporates a multi-staged and multi-disciplinary approach to identify suitable candidates. They argue that this approach leads to better outcomes, especially with many stakeholders including psychologists and social workers (Kumnig & Jowsey-Gregoire, 2015).

In sum, the existing literature suggests several ways that the social work role is potentially important in the experiences of transplant patients. They include: treating psychological conditions through counselling, organizing community resources for practical tasks for those with limited family supports, applying for medication coverage or income replacement programs, and providing emotional support to isolated individuals.

How Will this Research Build on Existing Work?

The work of Tong et al. (2013) aims to accentuate the recent contributions of qualitative research to transplantation practice and policy. These authors present a variety of qualitative methods used in transplantation research and identify integral principles to guide the evaluation of qualitative research (Tong et al., 2013). They argue qualitative research has provided insight into why socioeconomic inequities in access and barriers to organ donation and transplantation exist, why patients are non-adherent to anti-rejection medication, how patients cope with the various outcomes of transplantation, and patients' attitudes toward increased risk donor kidneys (Tong et al., 2013). They suggest interviews are useful for gaining insight into people's experiences, values, and attitudes to inform healthcare practice and policy (Tong et al., 2013). Tong and colleagues conclude by emphasizing there is unique insight that qualitative research provides in informing clinical practice and policy to improve outcomes in transplantation (Tong et al., 2013). They suggest an intersection of social science and transplant science (Tong et al., 2013).

Although several qualitative studies have been conducted from the patient experience, few have revealed the insight or perspective of individuals' feelings of preparedness from a psychosocial stance. There appears to be a gap in research with regards to patients' perspectives of their preparatory work prior to transplantation for example, instrumental tasks, or mental health counselling. My study will build upon preexisting work and explore the need for further social work support along the transplant journey as research identifies the value in treating individuals with a holistic approach.

Chapter Three: Theoretical Framework and Methodology

The theoretical perspective I drew upon as a means to analyze my interview data is Critical Disability Studies (CDS). I reviewed an array of information on the subject of CDS and felt it aligned with my sample population who live with chronic illness. Frazee, Gilmour, and Mykitiuk (2006) outline critical disability theory as the causes of disability being located within society and social organization rather than within the individual (as cited in Fudge Schormans, 2010).

The findings of Fudge Schormans (2010) resonated with me because my intention for this thesis project was to allow patients' space to reflect upon their experiences with renal transplant surgery in order to learn ways to aid in preparation and recovery from their perspective. Fudge Schormans (2010) discusses the "What's Wrong with This Picture" project and its purpose to enhance knowledge about people with intellectual disabilities by examining public photographic representation. Fudge Schormans (2010) also highlights the power differential between social workers and clients. The participants did not feel social workers understood them, their lives, or the impact of the ways they are treated by social workers and non-disabled people (Fudge Schormans, 2010). This exercise was also an opportunity to teach social workers, allowing for new kinds of learning and to facilitate change by listening to an oppressed group (Fudge Schormans, 2010). This thesis allowed me to demonstrate the CDS lens by listening to the participants in an attempt to facilitate change and to try and understand participants from their perspective, in parallel with Fudge Schorman's (2010) study.

Basic Theoretical Assumptions

There are many theoretical assumptions behind CDS. Firstly, that disability is located within social, cultural, economic, and political registers (Goodley, 2013). Rather than adopting the medicalized and pathologized lens of disability being located within the individual, CDS explores the ways that our capitalistic society materializes individuals (Goodley, 2013). Our society places emphasis on the marketability of individuals into the work force rather than supporting one another to survive and have our basic human needs met. Many individuals with disabilities receive social assistance and are discriminated against as being lazy or undeserving.

Much of the CDS perspective is focused on the able society versus the disabled. CDS discusses the dominant hegemony of the able society (Goodley, 2013). Society is dominated by the able body rather than the inclusion of individuals living with a disability. Goodley (2013) states, “a key site of the oppression of disabled people pertains to those moments when they are judged to fail to match up to the ideal individual” (p. 639). Campbell (2008) suggests that CDS refocus attention away from disabled onto the abled (as cited in Goodley, 2013). These ableist processes create a standard which presumes “ablebodiedness” and causes individuals with disabilities to see themselves as broken and unable to lead an independent life (Goodley, 2013). In turn, Goodley (2013) argues that people with disabilities suffer the “psychologization” of ableism. Goodley (2013) suggests, “our task must be to recapture the self from its position as Other” (p. 640).

There were many ways to incorporate the CDS lens into the data analysis of this thesis. Goodley (2013) suggests, “one of the key tasks of CDS is to explain how conditions of dominance crisscross in ways that promote values and, simultaneously, justify forms of oppression such as disablism, racism, homophobia, and orientalism that negate the existence of Others" (p. 637). Fudge Schormans (2010) describes Levinas' concept of the Other as the person before you needing your assistance and alterity being our "uniqueness." Differences do not automatically create alterity but rather alterity determines difference (Fudge Schormans, 2010). These concepts push us to pursue social justice by re-evaluating our views of disability and caring about, attributing value, and finding a place for people with disabilities rather than medicalizing and taking care of the individuals (Fudge Schormans, 2010). Meekosha and Shuttleworth (2009) describe key concepts of CDS:

> How societies divide 'normal' and 'abnormal' bodies is central to the production and sustenance of what it means to be human in society. It defines access to nations and communities. It determines choice and participation in civic life. It determines what constitutes 'rational' men and women and who should have the right to be part of society and who should not. (p. 65)

Social workers often lose sight of the ways Western culture has clouded our outlook and perspectives. Leake and Scouge (2014) discuss the concepts of autonomy and initiative as Western societal constructs rather than universally valued traits (as cited in Jordan & Tseris, 2018). Slater (2015) challenges the concept of autonomy as being privileged within a neoliberal agenda resulting in a reduced capacity to view the worlds of many adults as being filled by interdependence rather than autonomy (as cited in Jordan & Tseris, 2018). Professional interventions are often approached by the promotion of independence in conjunction with the definition of disability that focuses on functional deficits within the individual (Goble, 2004; Jordan & Tseris, 2018). Goble (2004) argues that people with disabilities are then viewed as defective because their performance is compared against normative standards (as cited in Jordan & Tseris, 2018). CDS is also focused on power dynamics, particularly surrounding gender and disability including issues of sterilization and abortion (Meekosha & Shuttleworth, 2009).

Questions Around Which Inquiry is Based

CDS focuses on ways in which society creates barriers for individuals living with a disability. Jordan and Tseris (2018) discuss the concept of the idealization of a normative body. They argue this concept results in “expectations imposed upon people labelled as disabled that they mimic, as closely as possible, the achievement of normative developmental tasks, or that they meekly accept their inability to do so” (Jordan & Tseris, 2018, p. 429). Society expects individuals with disabilities to comply with all medical treatments crafted to rehabilitate their differences and to demonstrate they are accepting of their disability as a means to reduce the discomfort of others (Jordan & Tseris, 2018). People with disabilities are taught to keep low expectations of what they can achieve which ultimately translates into the idea that they have an abnormal condition (Jordan & Tseris, 2018).

People living with disabilities face exclusion every day. Priestley (2003) and Scherer (2005) argue people with disabilities experience exclusion from critical areas of life including: education, employment, family life, political participation, and cultural representation (as cited in Jordan & Tseris, 2018). Wehbi and El-Lahib (2007) state “the low employment rates of disabled people are best understood as due not to an inability to work, but as a result of systemically ableist perceptions and practices within the labour market" (as cited in Jordan & Tseris, 2018). Jordan and Tseris (2018) critique Erikson's Eight Stages of Man through a CDS lens. Priestley (2003) argues that these developmental stages oppress individuals living with disabilities because Erikson promotes the idea that it is most appropriate to promote medical treatment to amend their differences or to help people with disabilities accept their limitations and less valued societal roles (as cited in Jordan & Tseris, 2018).

This critique was very interesting to me because Erikson's Eight Stages of Man are an integral part of undergraduate studies in the social sciences. Reviewing the stages from a CDS lens was very shocking because it appears to be at the forefront of how human beings become labelled as disabled or different and oppressed beginning during childhood. Jordan & Tseris (2018) conclude by stating, "disabled people are routinely compared against strict developmental markers, leading to pejorative labels such as 'abnormal' and 'vulnerable,' in comparison to 'normal' or 'successful' adult pathways" (p. 441). This quote articulates the ways in which individuals with disabilities have deeply engrained societal barriers placed upon them; it is these barriers CDS attempts to challenge or negate. Meekosha and Shuttleworth (2009) suggest, "the question amongst CDS has become how to conceptualize a diversity within a radical agenda to restructure cultural meanings, social processes, and a carnally relevant politics" (p. 56).

Goodley (2013) discusses the meaning of bodies in relation to CDS, and draws on Butler's three important questions of bodies in reference to disability:

> How are non-disabled bodies made more seemingly viable and desirable than non-disabled bodies? How do societal practices uphold the precarious higher status of non-disabled people through the abjection (rejection) of disabled people? In what ways do disabled bodies rearticulate what qualifies as a body that matters? (p. 636)

These three questions prompted deep reflection as I thought about the meaning behind them, acknowledging my privilege as an able-bodied individual. I thought about the ways society materializes men and women through social media representation and the unrealistic expectations set by celebrities and computer-generated photo editing programs. Social media is another way that people with disabilities are ostracized from society and yet another means of rejection. I wonder how individuals living with disabilities may view themselves with this added layer of complexity and unrealistic expectations set by our capitalist society?

Why is this Frame Compelling?

Critical disability theory applies to my thesis topic because the people I meet with as a social worker and the people I involved in this study live with many physical disabilities including end-stage renal disease. This population is often pathologized as “non-contributors” of society. Through my thesis interviews I utilized the social worker/client power differential to learn from the client perspective. I listened to their perspectives about transplant surgery and attempted to gain perspective from patients about how they feel they could have been better prepared for surgery by the transplant health care team. This frame is also compelling to me because it allows social workers to re-examine their roles in working with individuals who have a disability. Meekosha and Dowse (2007) critique the dominant narrative of medical social workers and argue we are at risk of becoming agents of social exclusion because we are influenced by discourses of disability that view people of impairments as in need of treatment, cure, or regulation (as cited in Jordan & Tseris, 2018).

As a medical social worker, I agree that this dominant narrative occurs within a hospital setting. Social workers are expected by medical practitioners to fix the social issues identified upon admission to hospital as a means to facilitate quick discharges and lessen the fiscal expense rather than acknowledging the deep-rooted societal issues that impact patient lives. My goal was to challenge my own lens as I have become accustomed to "fixing" individuals when they present to hospital and instead learn from their examples and inquire about what they feel would be helpful to them. Meekosha and Dowse (2007) suggest a participatory approach that respects and starts with the views of individuals with disabilities, shifting the focus of human services workers away from fixing individuals to the enactment of human rights through the redistribution of resources and power (as cited in Jordan & Tseris, 2018).

Implications of Critical Disability Studies for Data Analysis

CDS encompasses a variety of components that can be incorporated into data analysis. Dirth and Branscombe (2018) outline three components to their CDS research agenda: anti-individualistic epistemology, emphasis on disability as dynamic, and prioritizing marginalized perspectives. Dirth and Branscombe (2018) describe these components as rebutting the biomedical model of disability, reconceptualizing the meaning of disability, and emphasizing that individuals with disabilities are the experts of their experiences. These three concepts are woven into my research study as a means to analyze the interview data by thoroughly analyzing patient responses and paying close attention to the ways in which they respond. The CDS frame focuses on various dimensions, features, qualities, and characteristics of my data including: responses from the sample population, critically analyzing the transcripts from a disability perspective, keeping in mind the nuances of this theory including individualization of their issues, and comparing themselves to the “ableist” society. I interacted with patients as the experts of their experiences and looked to them for clear recommendations on how social workers can walk through their journey through the health system and attempt to lessen the burden.

In addition to carefully exploring how patients answered the specific questions I asked in the interview about their preparation for transplant and their experiences of recovery, I also asked questions framed by a critical disability lens. The questions I asked of the data included: are patients individualizing their disability and faulting themselves if they have not been able to reintegrate into the work force post-transplant surgery? Are patients feeling as though my study is insinuating social workers must fix them pre- and post-operatively by inquiring if there could be a greater capacity to the social work role within the transplant clinic? Do patients view themselves as contributing less to society than people who are healthy? Are patients constantly comparing themselves to healthy individuals and considering themselves to be unsuccessful if they are unmarried and reside with their parents? Do patients compare themselves to “normal” individuals who have "normal" bodily conditions? Post-transplant patients require a strict medication regimen consisting of immunosuppression medications, often steroids, which sometimes causes swelling and weight gain. I wonder if patients critique their appearance as being "different" if they do not look like "normal" individuals?

I also wondered if individuals felt they are too controlled by the medical system and perhaps feel like they do not wish to take their medication and uphold standards impressed upon them through the transplant clinic. I contemplated if patients wished for more freedom and less pressure to lead a lifestyle more similar to individuals without disabilities.

Limitations of the Critical Disability Studies Frame

There were very few limitations of the CDS perspective found in my literature search. Some authors including Goodley (2013) critique CDS as losing touch with the material problems of individuals living with disabilities. Barnes (2012) suggests theory has been placed above politics which causes society to lose sight of the global economic crisis that threatens to place people with disabilities in vulnerable and devalued societal positions (as cited in Goodley, 2013). Shakespeare (2010) suggests CDS is settling into the field of academia rather than being recognized as a phenomenon around which to band together and campaign (as cited in Goodley, 2013). Goodley (2013) concludes, "CDS have not developed simply to capture the theoretical interests of scholars, but have developed theories that are in concert with contemporary lives, the complexities of alienation and rich hopes of resistance" (p. 641). CDS may then be viewed as a platform through which to think, act, resist, relate, communicate, engage with one another against oppression and discrimination (Goodley, 2013).

In conclusion, CDS attempts to be relevant to a range of individuals living with various forms of disabilities including physical and intellectual. CDS also has the ability to encompass gender studies as it reflects upon ways females experience forms of disability. As a medical social worker, I was interested in learning from the patient perspective and utilizing their perspectives into workplace practice given their expert knowledge regarding their disabilities. I hope to incorporate their insights into my psychosocial assessments pre-renal transplantation and enhance the overall patient experience by taking their lead.

Methodology

This study was reviewed by the Hamilton Integrated Research Ethics Board (HiREB) (see Appendix A). Recruitment for the study was completed during May 2019 by transplant nephrologists at SJHH, who, along with their nurses, provided deceased donor renal transplant patients who were one to six months post-op with my recruitment letter (see Appendix B) inviting them to participate in my one-time telephone interview. To avoid patients feeling pressured to take part, I did not ask them directly to participate in my study, and the recruitment letter along with consent for contact (see Appendix C) assured them that their physician would not know who participated and who did not. There was a total of 11 participants recruited, all whom either met with me in the transplant clinic to provide written consent (see Appendix D) or provided their information for me to contact them directly by e-mail or telephone to obtain verbal consent and participate in the one-time telephone interview. Of the 11 individuals who agreed to be contacted, five could not be reached.

Six people who had received a kidney transplant participated in my study. Of the participant group, four were male, and two were female. Two participants were single, two were widowed, and two were married. Two participants maintain employment, three are retired, and one is unemployed. Their stage of recovery ranged between one to six months.

Upon contact, I reviewed parts of the questionnaire in order for them to consider possible answers to my questions prior to the interview. All participants provided written consent. I conducted telephone interviews participants during the month of May 2019, at a time that was mutually convenient. Interviews were between 30-60 minutes and semi-structured (see Appendix E). Each interview was audio recorded, using a digital recorder, then transcribed verbatim by a transcriptionist who signed an oath of confidentiality form (see Appendix F).

Participants were given many opportunities to ask questions throughout the interview. I would frequently ask if they were comfortable with what information they shared or if they had any concerns. Participants were very forthcoming as I took a non-expert stance throughout the interview. All participants were given a $25.00 honorarium for their participation.

A qualitative analysis data program “Quirkos” was used to code the data (DeCuir-Gunby, Marshall, & McCulloch, 2011). Thematic analysis was used to make sense of the codes observed through using “Quirkos” (Ryan & Bernard, 2003). Pseudonyms were used to replace any reference to patients, family members, health care providers, and organizations in the transcripts in order to address confidentiality. Names of participants were not shared with anyone from the hospital. All participants will be given a summary of the study's results as requested.

Ethical Considerations

I hold a full-time position within the Kidney and Urinary program as a registered social worker on the frontline at St. Joseph's Healthcare Hamilton (SJHH). I accepted a one-year temporary full-time position that began March 4, 2019 in the outpatient Respirology program and was not working within the Kidney and Urinary program in any capacity during the time frame of this research study. I ensured I had not had any contact with participants in my social work role in the pre-transplant clinic or inpatient Nephrology unit by referencing our excel spreadsheet which tracks all social work referrals and the corresponding social worker who assessed each patient. I will ensure I do not meet with participants in the future upon returning to my position in 2020 by referring to an alternate social worker.

Chapter Four: Findings

The participants of this study provided a wide range of post-operative experiences after receiving a renal transplant. After completing an in-depth review of each transcript and then considering them as a whole, I identified five key themes. These themes include: variability of transplant preparation, hopes, experiences, and perspectives of recovery, meanings of recovery, significance of social and economic supports in recovery, and the role of professional staff in providing support and resources during the transplant journey.

As noted earlier, participants were assigned a pseudonym to preserve their identities and foster confidentiality in this study. The participants pseudonyms are as follows: Richard, Barbara, Christine, Kyle, Robert, and Hassan. These names will be used throughout the findings section and correspond with the direct quotations provided by each participant.

Variability of Transplant Preparation

In discussing their journeys toward transplantation, participants in my study spoke about the many dimensions involved with preparation. Each participant completed their own preparation that varied between major and minor levels of interventions. Their stories highlight medical, social, emotional preparation, and the significant variability in the experiences of individuals in the lead up to transplantation.

In order for Robert to qualify for a kidney transplant, he underwent the standardized tests but was also required to lose weight:

> *Yah. Well, I had bariatric, see to get the kidney I had to lose a lot of weight. I lost almost 100 and 130 or 135 pounds. So, to be able to do that I had bariatric surgery.*

Robert explained how he recovers quite easily from surgeries and was home within one day of having the bariatric procedure. He also shared how he had a subsequent surgery approximately one month later, having his gallbladder removed, as a result of having bariatric surgery. Robert underwent a total of three surgeries including his kidney transplant.

In contrast to Robert's preparation, Hassan experienced a different preparatory phase. The time span Hassan waited between when he was placed on the list to when the transplant surgery occurred was less than two months. When asked about his preparation for surgery, Hassan explained:

> *No like, as I said it was quite sudden. Although they told me what to expect, like be ready, to pack and head to the hospital.*

In terms of preparation for transplant by means of instrumental tasks, Richard sold his house and moved into a condominium in order to minimize home maintenance duties after surgery. This task also proved to be an emotional one as Richard disclosed the passing of his wife two years prior. Robert, Hassan, and Richard's experiences preparing for transplant surgery are vastly different, capturing the nuances of patients' work-up phase from packing a bag, selling one's home, to undergoing bariatric surgery. Their waiting times also appeared to impact the variability in preparation as some participants had more time than others to prepare.

The medical workup prior to transplant is extensive. It is not uncommon that other health issues are discovered over the course of the process. At one point in her journey Barbara, for example, learned she had a condition that could preclude her getting a transplant. Ultimately Barbara appreciated that the regular testing had revealed the condition:

> *If I hadn't been getting the tests, I would never had discovered the problem to begin with and it could have been much, much worse. So, believe me I was glad they found what they found when they found it.*

At the same time, it was a major health problem, requiring the removal of both of her kidneys secondary to cancer. While Barbara recovered well and went on to receive a transplant, her story shows that the medical path towards transplant can be long and taxing for patients.

During Richard's complicated journey, he was diagnosed with a condition that impacts the clotting factor in his blood. He described the shock he felt when hearing this news as he was told he would have had it since birth. It was not until he underwent the medical work-up for transplant that this condition was revealed. Richard described this experience to be confusing for him as he learned about this new diagnosis in the context of being worked up for a transplant, emphasizing how the process impacts patients in various ways.

Participants explained the various ways by which the preparation/work-up phase were physically taxing. It is important to also identify how the process impacts individuals from a psychological perspective. Christine described her experiences from the perspective as a second time transplant recipient. Her first transplant was from her brother who was a live donor. Her most recent transplant surgery was from a deceased donor. She described how the live donor process went quickly for her the first time around and how with the deceased donor transplant, she expected to be on the waiting list for many years. Christine reflected on the wait:

> *I always tried to be more realistic and I just took it with a grain of salt, and just prepared myself really to be on dialysis for a while…I wasn't really thinking much about the surgery itself…I was just going to work, doing my dialysis and, you know, take it day by day. And I guess with me working full-time it really helped me to keep my mind off of it. It was sort of like therapy.*

Here Christine appears to be avoiding thinking too much about the surgery: she is preparing herself mentally to be on dialysis for some time. Working full-time in the months prior to learning that her transplant would go forward helped keep her mind off it. Like many transplant patients, she is hopeful but trying not to "get her hopes up."

Robert described the time period between when he was called into the hospital for a potential kidney match. He stated he arrived at the hospital at 11:00am and once informed that the surgery would go ahead, he waited until 10:00pm. He described this time frame as being "stressful" as he worried about the status of the new kidney, hoping that nothing would go wrong with it before it arrived at the hospital. Transplant recipients experience various worries along their preparatory phase, impacting their psychological state. Robert and Christine's experiences are examples of this.

After receiving a kidney transplant, Barbara experienced a fairly common post-operative condition called delayed graft function, meaning her new transplant did not begin working immediately after surgery. This experience caused her to reflect on the pre-transplant, preparation phase from a psychological standpoint. Barbara explained:

> *They literally started me at first by cutting down my dialysis time. I was still going three days a week but shorter periods and getting less dialysis at the time…it was pretty gradual but like I said it worked and I'm grateful they were right…but I've got to admit that if I had realized ahead of time that this was more likely that the statistics were that big, I might have been a little bit better prepared for, there were days when I was pretty depressed, let me put it that way. I kept thinking I've got to have the only kidney in town that won't work, you know.*

Here Barbara appears to be reflecting upon her psychological adjustment to experiencing a post-operative complication. She explains how she felt that she would have been better prepared mentally, had she been informed about the prevalence of delayed graft function in kidney transplant recipients during her work-up.

It appears that participants' transplant work-ups were vastly different in terms of ways they prepared across these domains and the medical diagnoses they received during this phase. Preparation for some was as simple as packing up a bag, whereas for others it was packing up an entire house. Experiences varied from low key to more significant as well as from pre-transplant medical interventions such as bariatric surgery, causing various levels of life disruption. The recovery phase proved to be equally diverse.

Recovery: Hopes, Experiences, and Perspectives

In a life filled with diagnostics and procedures, individuals with end-stage renal disease strive to attain a life that is less medicalized and without dialysis. Individuals awaiting transplant surgery experience various fears and worries throughout the process as the transplant offers a promise for a longer and healthier future.

Richard's worries prior to surgery primarily related to his children. He also appeared to be experiencing grief related to the passing of his wife two years prior to his transplant. The grief was intertwined amongst he and his family and may have carried into his thoughts prior to surgery. When asked about his greatest worry, Richard responded with:

> *…like I still want to watch my grandkids grow up. I know my wife wanted to badly, like she, she loved the kids…So, I know my daughter was really upset about that and just worried about the kids, wasn't really worried about myself.*

Richard's worries appear to be related to the longevity of his life and hope for what a transplant would mean for his future. Kyle's pre-operative worries were similar as he experienced a low red blood cell count (common for many dialysis patients) that required blood transfusions and a pause to his spot on the transplant list. He explained:

> *So, like a few months before I received the transplant I got a couple of calls and then they had to take me off the transplant list to get my hemoglobin, well, one to get my hemoglobin up to a level where they, it wouldn't, it would be easier, and two, they wanted to figure out what was causing it to be so low. I think that was the most concerning part because, they had to give me a blood transfusion but*

> *they always said if they ever had to do a blood transfusion, not to unless it was, like critical.*

Kyle's worries related to the status of his health prior to surgery and the hold that was placed on receiving a transplant due to his low red blood cell count. He had already been on the waiting list for five years due to the required weight loss he needed to achieve. Both Kyle and Richard were hoping to receive transplants in order to regain their health and longevity of their lifespan.

The transplant process offers hope of full recovery for each patient – yet, the trajectory of recovery is often not as smooth as patients hope for. Many participants in my study experienced complications. Robert, for example, experienced bladder dysfunction which he explained was attributed to years of dialysis when he did not urinate. He required an additional bladder surgery a few months after receiving his transplant. Richard had two heart attacks after surgery requiring another hospitalization in a specialized cardiac unit. He underwent various tests and trials of medications. Kyle experienced a post-operative infection requiring intravenous antibiotics. He indicated it was trial and error for the clinic and the Local Health Integration Network (LHIN) to determine where the best place to receive the medications were. Ultimately, he was connected to the LHIN and obtained his intravenous medications through a clinic closest to his home in Kitchener. As noted earlier, Barbara found that having to go on dialysis again was "a bit of a shock" and went on to say:

> *I have to admit that I wouldn't have minded being warned that 20 percent of the recovery, people who get transplants will run into this problem to some degree.*

In hindsight, participants in this study often came to realization of various things they wish they would have known more about.

Participants in my study had a range of post-operative experiences and luckily recovered from their complications. They were able to reflect upon what they wish they had more information on prior to surgery. Richard noted that he'd been given a booklet about what to look out for, and he said that anyone who read the whole booklet would understand the process. However, the timing of receiving the booklet was in his view a problem:

> *I think they should give you that booklet before you go in for the surgery – they give it to you after...*

Kyle on the other hand, due to having been called into hospital a few times for potential kidney matches prior to receiving one, had the opportunity to read this booklet prior to surgery as he was given the booklet ahead of having the surgery during one of his calls. Kyle felt that he was given ample information prior to surgery and that his post-operative trajectory was quite straightforward due to having read the booklet of information prior to surgery.

As previously discussed, Barbara wished she had received information about delayed graft function prior to surgery in order to have been more mentally prepared that this could be a possibility. Although hindsight allows us to see what information we wished we would have known in various situations, the transplant work-up process can be very overwhelming and information shared can either be forgotten about or missed, given the range of time between work-up and surgery. It is also not uncommon for recipients to receive more than one kidney throughout their lifetime, offering another layer of knowledge.

Undergoing major surgery allowed participants in my study the ability to self-reflect and offer insight to future recipients as to what they would inform them about. Christine, having had a transplant in the past, was able to share recommendations to future recipients after receiving her second kidney:

> *Basically, plan ahead like I did, make sure you have the support you need, especially like having somebody be available to drive you to and from the hospital which is a big thing. Especially for me because I'm in Kitchener…when I talked to the social worker, I asked, St. Joe's there was no service available within this area for let's say through the Kidney Foundation where somebody can drive me to and from the hospital because I'm not in the Hamilton area.*

It is important to note the disparity of services in outlying areas such as transportation. There are often more services available in major centres. The lack of services most often impacts those who do not have family support to rely on. Christine concluded by saying,

> *Basically, plan ahead, make sure you know that you have the support there and you have people you can depend on. Yah, and just…not to stress yourself out over little things like that you know, 'oh I can't do this or I can't do that' cause then you'll probably make yourself sicker if you do.*

Christine discussed the stress associated with putting pressure on oneself to complete tasks independently rather than asking for help. She believed that asking for help is a big part of the transplant recovery so not to further stress oneself. Kyle's advice offered a positive outlook to future recipients:

> *Just, I think it's just stay positive because like, because like once the surgery happens, it gets better.*

Meanings of Recovery

Participants in my study have highlighted how receiving a new organ is a promise of hope for full recovery. Although they remained hopeful, post-operative complications were identified. Along with the promise for hope of full recovery, participants strive for a life of normalcy rather than illness. However, receiving a new organ comes with its own care regimen and individuals are sometimes surprised when illness lingers or reappears. Many of participants' comments reflected a major theme in the critical disability studies literature, the meanings and significance of "normalcy."

Barbara's experience emphasizes the tension that patients often experience after surgery, when individuals are hopeful to regain a life of normalcy but are quickly reminded of their life long illness:

> *So, I went out and got myself, as I said, a pair of good slippers. Nobody warned me that because they have a tendency to encourage to drink lots of fluids immediately after surgery that my feet were going to swell and I couldn't get into my new slippers (laughs).*

Here Barbara discussed the purchase she made prior to surgery with the goal to recover immediately after surgery. This example demonstrates her strive toward normalcy. She discussed further:

> *I was walking around with, with, swollen feet for, like I said, about a month and a half and part of it was the fact that my body has a natural tendency to retain fluid which doesn't help, and part of it was because I wasn't, the kidney wasn't working, I was not getting rid of fluid unless I had dialysis and, they didn't want to take me down too close to the what they call the dry weight, okay. Because the kidney needs fluids in order to work, okay. So, it's, it's a juggling match…now mind you they, they handed me slipper socks and said 'these will work better' you know, and I was, I think I was still up and about but I don't think I wore slippers the entire time I was there because my feet were too swollen. But I never wore those slippers the entire time I was in the hospital. I can wear them now.*

The slippers appear to be a symbol of recovery for Barbara as she discussed how she now fits into the slippers after her kidney began working and her fluid levels were regulated.

Recipients of deceased donor transplants are accustomed to caring for themselves by means of attending dialysis sessions and taking various medications. Transplantation involves a new and complex medication regimen of immunosuppression and frequent appointments at the post-transplant clinic for close monitoring upon discharge from hospital. Recipients are instructed to monitor their blood pressure, weight, temperature, and blood sugars very closely in order to protect the new organ by anticipating any sign of infection. Richard's complicated post-operative trajectory involving two heart attacks added another layer of complexity to his care regimen. He described his care regimen:

> *So, I was still having problems with the heart. So, now they've got me on a nitro patch, I carry nitro and they can't give me certain meds that they wanted to give*

> *me because they did an angiogram on me while I was in there and they said that one of the arteries they patched is completely blocked… but they said they're going to try and treat it with oral meds… but then when I went back to the transplant clinic they said that 'we can't put you on that one because it affects the new kidney.' So, now I don't know what's going on. Like, I've seen so many doctors and they changed my drugs so many times it's confusing.*

Richard was able to use humour in his situation as a means of coping with his complex situation, but he also demonstrates the ways that organ transplantation can affect one's life and how learning the new regimen can be confusing. On the contrary, Kyle's experience was quite different. Kyle described his medication regimen as being "easier" and more "straightforward" than his previous because his medications were staggered throughout the day.

Participants spent time informing me about the ways their mood and morale played a role in their recovery. Many participants attributed the recovery of their transplant to the positive outlook they embodied. Hassan explained:

> *Well they say to think positive; I will heal faster and I did. They said it will take six months and mine was healed in four months.*

Hassan's short waiting time on the transplant list did not allow for much preparation for surgery. Despite the quick turnaround time of receiving an organ, Hassan came through surgery and recovered in a shorter time span than what he was told to expect.

Robert, on the other hand, emphasized the ways by which he was able to maintain a positive mood and morale. He reflected:

> *The family made sure they were around a lot more and that, they took me to different appointments and, this was afterwards, they took me around to all different appointments and, I had no worries or, or nothing like that. And, like I say my wife she, was fabulous she just looked after everything and, kept me high, kept me in a good mood and everything like that. That was one of the things that I was worried about because my transplant nephrologist told me that I could have, times of high and times of low, that I might get depressed, I might not get depressed and I was lucky I didn't get, too depressed. I got down a little bit but not much.*

Robert was informed by his physician about the impact transplantation could have on his mood. He worried about how this would affect his recovery. Robert attributed his "good mood" to the care he received from his wife and family, ultimately allowing space for him to feel a level of normalcy throughout his recovery.

Participants in my study were able to share the ways they intend to further achieve normalcy now that they have received a transplant and no longer require dialysis. Their recovery appears to have allowed for a comfort in knowing they have more freedom and control in how they choose to live their lives, demonstrating a connection to normalcy.

Richard received many visits from friendly faces while recovering in hospital after his transplant, aiding in his comfort. He informed me about one scenario that he enjoyed describing in a humorous way:

> *He brought the donut and I ate it and the nurse came in and she said 'I got to check your sugar level' and I went 'oh oh.' She checked my sugar and it was like*

> *21 or something like that she goes, 'what have you been eating?' And I said, 'I got chocolate all over my face' and she goes, 'ah never mind' and Tim goes, 'I'm getting out of here before I get blamed for this.'*

Despite the various ways that Richard's surgical recovery did not go as planned, he demonstrated a level of comfort he received when his friend visited and brought him a sweet treat. Simply eating a donut allowed Richard the choice and gave him a feeling of normalcy while recovering in hospital.

When asked about employment, Kyle stated he has not had the opportunity to attain meaningful work since being ill. He explained his future oriented goals:

> *Currently unemployed but, post-surgery I want to get, I want to start looking for a job now that my health seems to be a lot better.*

Kyle informed me of the various ways that his kidney transplant has allowed him to feel better including a reduction in his swelling/fluid retention, and an increase in energy level. He feels he has now gained the physical capacity and choice to enter the work force, which again demonstrates a level of comfort and normalcy for his future endeavors. The feelings of comfort and normalcy appear to also be connected to the level of social support received through connection with family and friends.

Significance of Social and Economic Supports in Recovery

The common thread amongst all participants in my study was the profound level of support each received pre- and post-operatively. Their support systems consisted of various individuals including spouses, siblings, parents, aunts/uncles, friends, and co-workers. These important people in the lives of the participants intervened in many ways including through providing emotional support and support with instrumental tasks such as transportation or wound care, proving to be a vital component of the recovery of each participant in my study. Richard emphasized the support he received from his brother:

> *Well I got, I've got a really good family. So, I wasn't worried about any of it and then, when I sold the house, because we had to wait for the closing date on the condo, I stayed at my brother's place for almost a month and, he said, 'when you go in for the surgery, if you have to come to, somebody has to look after you, you come back to the house and stay with us.'*

Not only did Richard's brother assist him with organizing the preparation and sale of his home, he provided him with a space to recover from, surrounded by family.

Christine also received immense support from her family. She provided a thorough description of what her recovery entailed and how her brother intervened:

> *Well the planning that I did, like obviously I couldn't drive. They said no driving for at least 6-8 weeks and don't lift anything more than 5 lbs. or something like that. So, those were the, the things I needed to plan for – to get people to drive me to and from the hospital. My brother's always here like picking up groceries for me or cooking for me, things like that. Like my family as well, my aunt she was cooking as well. So, I didn't have any problems with anything like that.*

Christine's informal support system intervened in many instrumental ways, allowing for a seamless transition home from the hospital. She was also able to pay privately for someone to clean her home. Christine's experience was unique since she had recalled what level of support she would need based on her first transplant experience.

Barbara appreciated the perspective shared with her by a previous transplant recipient she met in clinic. Barbara reflected on how she valued this connection:

> *And, I find that, like I said talk to anybody you can find who's already been there, I haven't, I didn't have any really in-depth conversations but I remember being in the transplant clinic on a pre-surgical visit and sitting next to somebody who had just had a transplant fairly recently and just chatting and, she was very willing to share her experiences and like I said it was, really one-to-one really works beautifully if you know what I mean. There's, most people who've had it are only too happy to pass on, whatever advice they can, they come up and it's different for every person.*

Barbara appeared to enjoy the one-to-one interaction held with a fellow transplant recipient in clinic. Richard also demonstrated the significance of speaking to his cousin who had received a transplant in previous years stating how his cousin gave him a lot of useful information allowing him to feel like he knew "what was going on." Richard seized every opportunity he had in order to communicate with individuals who had received a transplant. He even sought out individuals in the dialysis unit to speak to. Having had a transplant in previous years, Christine also felt more aware of what the second transplant would entail. She described:

> *Because this would be my second kidney transplant, I sort of remember or knew what to expect. So, I didn't have a lot of concerns.*

Overall, participants found the knowledge of previous recipients or the knowledge they received as being a prior recipient to be a helpful resource that aided in their recovery and fostered positivity.

Participants spoke a great deal about how having a positive outlook enhanced their recovery. The positive outlook and strong influence of family support caused me to wonder about the connection between the two and how they both facilitate the transplant recovery. Robert's wife supported him in many ways. He summarized the involvement of his wife and family:

> *I was lucky enough that I got a great wife and she took time off of work and she got on that, program where they pay you to look after who's ever sick for, I forget how many weeks it was, 15 weeks, I think. Yah, and so she was with me for 15 weeks and by the time the 15 weeks were over I was, had everything. The only thing that, the last week I made sure that I was able to look after all the pills.*

Robert's example highlights the instrumental ways that family involvement helped throughout his journey, allowing him to move forward during recovery. His story also points to the significance of public programs that support informal care in the community. He also explained how his family supported him emotionally:

> *They were very, supportive and, of course, my family that was the most important – my family was all behind, you know, kind of 'rah, rah, rah', stuff.*

The two types of supportive intervention appear to enable Robert to personify a positive outlook throughout his transplant journey.

Hassan experienced a gap in care in his journey upon discharge home from hospital. He informed me that wound care nursing was organized for him prior to discharge as he required specialized dressing changes for his incision. He was also supposed to receive assistance with personal care from a personal support worker. Hassan explained that the service was delayed by one week, meaning he and his wife needed to complete the dressing changes and personal care on their own. Given the fact that Hassan was just discharged from hospital after undergoing organ transplant surgery, he was clearly in a vulnerable state. Hassan's wife was able to step in and help him during a crucial part of his recovery, which he was grateful for. Hassan did not let this experience interfere with his recovery as he went on to tell me (as previously mentioned) how his wound ended up healing more quickly than anticipated. The support of Hassan's wife may be linked to his positivity as Hassan spoke many times about the power of having a positive attitude.

It is important to note that families often find themselves completing these types of caregiving duties in lieu of what the government programs are supposed to provide. It can be concerning since Hassan's wound care was supposed to have been completed by a regulated health professional as prescribed by his physician. The care from family often gets overlooked and increases the stress levels of the patient and caregiver when these unexpected tasks arise. If a patient does not have a family member to intervene in this type of scenario, it often contributes to re-hospitalization. Hassan had both felt care and support and material care and support, allowing for a timely recovery.

Public/government resources are also very helpful in the context of seniors' benefits. Hassan also described how these resources helped him. Many participants in my study were over the age of 65. This age bracket puts them in the category to receive medication coverage through the Ontario Drug Benefit, meaning their medications (including the new immunosuppression medications) are financially covered by the government. If transplant recipients do not have medication coverage, their medication has the potential to reach thousands of dollars per month. Hassan, Barbara, Richard, and Robert all have this benefit. Christine has private coverage through her employer and Kyle has coverage through Ontario Disability Support Program (ODSP).

When asked about receiving assistance with organizing application to financial coverage programs after transplantation, Kyle voiced:

> *There wasn't really anything cause I, most of my finance was coming through ODSP.*

Kyle also shared how ODSP covered the cost of taking a taxi between Kitchener and Hamilton to attend his follow-up appointments at the post-transplant clinic. If Kyle was not receiving ODSP, he would have been forced to pay out of pocket for his taxi rides if nobody was available to provide transportation during his driving restriction period. Receiving a transplant can place a financial strain on individuals not receiving employee or government benefits. The participants in my study were well equipped to financially support themselves after surgery, and live in a province that provides certain very important benefits publicly, allowing them to obtain the prescribed medications and attend regular follow-up appointments. Professional staff can also be a means of support during the transplant journey, including facilitating the coordination of these instrumental tasks.

Role of Professional Staff in Providing Support and Resources During the Transplant Journey

Throughout the transplant journey, patients encounter a wide variety of health professionals including: transplant nephrologist, urologist, nurses, physiotherapist, pharmacist, dietitian, and social worker. This specialized team is trained to intervene along the journey of transplant recipients in various ways. Participants in my study spoke most frequently about the support provided by their health care team.

Robert felt a strong connection with his transplant nephrologist. Much of his interview was spent discussing the ways he felt supported by her. Robert explained:

> *Yah, I think my transplant nephrologist was, she was on the floor every day. What I did appreciate was, and I know I keep repeating this, but my transplant nephrologist is a person that really brings you up, you know what I mean. She makes you feel, feel really good about yourself and about everything. So, I, I have to give credit where credit is due. She helped a tremendous amount of time.*

Robert felt that the presence of his transplant nephrologist on a daily basis while he was in hospital helped boost his morale. He also informed me about how she would explain his condition to each family member that visited. Robert credited her for the amount of time she spent with he and his family and how grateful he was to have her along his journey. Similarly, Richard appreciated how “easy” it was to speak with his doctors and felt like he was with “normal people” when they were explaining things to him. Richard’s experience demonstrated the importance of personally connecting with his medical team and the positive influence of emotional support from the hospital staff during his recovery.

Barbara highlighted the nuances of how nurses were helpful and supportive during her time recovering from transplant in hospital. She described a scenario that would be relatable to most people recovering from surgery:

> *I found some extremely, extremely nice, people and, and they're very, very well trained not to make you feel embarrassed which is a good thing considering what, you know, like I said the subject matter. I mean if you're in the hospital and you need help bathing, for instance, it's kind of nice not to be squeamish about it and not to have the feeling that he's looking at me and I'm fat, you know. No they, they, the nurses were all extremely nice and very helpful. I mean they volunteer all sorts of things I wouldn't have thought to ask of them, if you know what I mean.*

The professionalism demonstrated by nursing staff allowed Barbara to feel comfortable, in an uncomfortable environment, recovering in hospital. The active sharing of anecdotes that patients do not know to ask about is often very valued. This unwavering support from hospital staff can sometimes be missed once individuals move onto the next phase in their journey.

After years of dialysis treatments, transplant recipients often develop a sense of connection and rapport with the staff involved in their care. Patients who receive hemodialysis treatments are prescribed a various number of sessions per week, most often thrice for between three to four hours. During these sessions, patients interact with the various staff members, their roles previously identified. This group of professional staff get to know patients on a deeper level, given the times per week over the course of usually several years. Patients grow accustomed to regularly interacting with the same people several times per week, for years. Once transplanted, the reality of no longer requiring dialysis sets in, in a freeing, positive way. The next realization is often the loss of the staff members from the dialysis unit, while integrating with the new transplant team. Richard described how he felt after no longer requiring dialysis:

> *Oh, family and friends were fantastic, but I think the dialysis people were even better because when I went back down to clean out my locker and say goodbye to everybody it was like, I don't know, I kind of miss them all now.*

Richard pointed out how helpful his family members and friends were throughout his journey. He made a powerful statement when suggesting his dialysis team were "even better."

Participants in my study alluded to the ways they found social workers helpful, but coincidentally, a few participants felt that since they had strong support systems, the social work involvement they required was minimal. Kyle described an interaction he had with his post-transplant social worker,

> *And, like again the social workers said if I never needed help getting like, like getting to the clinic to contact them ASAP and they should be able to do something about it.*

In this situation, although Kyle did not require assistance with transportation, he described how his social worker made themselves available for Kyle's future needs should he require assistance. Knowing they could be available in the future if necessary seemed to have allowed Kyle to feel a level of comfort should unanticipated needs arise.

Barbara described how social workers can intervene from an instrumental perspective, specifically regarding resource counselling/finances:

> *Yah, there are a few things that I'm still wanting to ask 'cause I had, for instance, when I came in and started, dialysis, at hemodialysis, the local social worker who covered my particular, venue, okay literally came up and informed me that I was entitled to a tax credit okay. Everybody who's on dialysis is entitled to a tax credit because they assume that in dialysis no matter how much of it is paid for by the state, there are a lot of auxiliary expenses attached and it's true. But they give you like a $1500 tax credit. Now that I no longer am on dialysis and because I have a kidney I'm assuming that I don't get that credit anymore but I'm going to check before (laughs) I give it up just in case because for a while there, at least, they have you coming in the clinic several times a week, in some cases, and at least once a week other times and, like I said, that's for some people the trip in and out has got to be expensive compared to what mine is.*

Here Barbara describes a scenario where she was approached by her dialysis social worker and informed about a financial resource that dialysis patients are entitled to. She also describes the financial challenges associated with transplantation and how the tax credit has the potential for elimination, causing further financial strain on patients. Social workers have a wide knowledge base on financial resources available to patients and the ability to facilitate patient advocacy by means of assisting with these often-complex applications. The various strains placed on patients, such as medical complications or instrumental tasks, can often impact their outlook or morale.

Barbara and Robert mentioned how their post-operative complications contributed to low mood/depression during the earlier phase of their recovery. Social workers have the ability to intervene during this phase of recovery because they are trained in specialized counselling techniques. This appears to be one of the ways that the social work role could have been helpful for Barbara and Robert during their recovery.

Robert, commented on the availability, or lack thereof, from social work staff:

> *I found social workers were, well the one that I had seemed to be always in a hurry. Every time, like I had met them once before, years before and I met them again, and this time they always seemed to be in a hurry to go somewhere. So that's, the social workers got to take a little bit more time and not be in such a hurry.*

Here Robert demonstrates how he would have appreciated more time from the social worker he interacted with pre-transplant. This specific area of social work involvement tends to be less available due to time constraints secondary to staffing issues. Unfortunately, Robert's experience sheds light onto the ways patients may feel the effects of limited resources and how further intervention from a social worker may have been helpful during the pre-transplant phase.

Richard had a unique experience as he described the ways his dialysis social worker integrated himself into the various phases of his care (social workers are typically assigned to either inpatient or outpatient, pre- or post-transplant clinic, outpatient dialysis, or inpatient nephrology or transplant units):

> *In fact, he came and seen me in the hospital, it was great. Even when I was on dialysis he would come over and sit down and talk to me for like an hour…and, and it, I don't know, it just kind of eased everything, it made things go a little bit easier.*

The social worker from Richard's dialysis unit seems to have provided a level of support that transferred into the support along his entire journey with end-stage renal disease. Richard appears to have benefited from supportive counselling and the mere consistency/presence, demonstrating the power of emotional support social workers can have amongst one's journey amongst the health system. Ultimately, participants' commentary summarized the ways by which they found the social work role to be helpful across their varied experiences.

Chapter Five: Discussion and Conclusion

How Does this Study Contribute to the Literature and Theory?

This study sent out to investigate the preparatory experiences of people who have had renal transplant surgery one to six months ago and the relation to the social work role. The narratives of the six participants in the study offered insights along a number of dimensions. My analysis highlighted the importance to participants of knowing prior to their surgery what to expect in the post-operative phase; of their achieving a sense of normalcy and control; the importance of a social support network; and the many meanings of recovery. Participants' experiences point to the importance of the initial psychosocial assessment completed by the social worker pre-transplant, that enables understanding of the patient's life overall, health circumstances, and economic constraints. This study also reflected various themes in the wider literature. Furthermore, my study revealed various implications for social work practice which will later be reviewed during this chapter. Lastly, the limitations of this study will be discussed followed by concluding remarks.

What Do Patients Wish to Know?

Throughout my interviews, participants often shared elements of their post-operative journey they wished they had known more about prior to receiving a renal transplant, specific to their medical outcomes. Barbara spent a portion of her interview discussing her need for post-operative dialysis and how she was unaware of this prior to surgery. She identified the statistic she was informed about in relation to the percentage of people who require post-operative dialysis and how she wished she had known about this prior to surgery because she may have been able to adjust her expectations accordingly.

Another area of post-operative care that participants wished they had known more about prior to surgery was their care regimen after receiving a transplant. Richard specifically pointed out how the education booklet provided post-operatively shared a number of recommendations including how to monitor yourself for infection including the incision site. Richard felt that it would have been more helpful for him to have read this information during the pre-operative phase of his journey.

Along a similar vein, Kyle had an opportunity that the rest of the participants did not have. When Kyle described being called in by his transplant nephrologist for a potential kidney match several times prior to having the surgery, he shared that he received the post-operative education booklet during one of these times. Kyle took this opportunity and read the education booklet at home prior to when he actually received a kidney. He explained that reading this booklet prior to receiving his transplant allowed him to feel like he knew what to expect after surgery, and in turn, felt like he was prepared to handle the post-operative care regimen.

One participant had a unique experience as she had received a renal transplant in previous years from her brother. Christine did not appear to have the same post-operative concerns, pre-operatively that other participants had. During her interview, she explained how having her first transplant had mentally prepared her for what was to come during her second transplant. She knew to expect pain and to prepare for the facets of her post-operative care including applying for short-term disability through her employer, organizing transportation to Hamilton, and the cognizance to worry less. In a similar token, she did not feel there was any missing information for her that she was unaware of prior to receiving her second transplant.

The notion of wanting to "know more" was a new element to renal care that I did not come across during the conduction of my research. I did not find this type of literature in relation to renal care specifically, but there is literature about surgery more generally that reflects on the value of this. Adams and Pearlman (1977) describe anticipatory guidance as,

> A technique of informing the patient in a detailed way about all aspects of the upcoming intervention, including: the need for surgery, the degree of pain and disability to be expected, type of anaesthesia to be used, some information about the post-operative course, and the expected disability following surgery on either a temporary or permanent basis. (p. 1161)

Participants in my study reflected how they desired further information about the various surgical outcomes because they felt knowing more about what to expect would allow them to adjust their expectations, and their lives, for the unknown after-surgery realities.

I feel this learning could be expanded to reflect the work of Gordon and colleagues' (2013) about "opportunities for shared decision making in kidney transplantation." This study highlights the importance of informed consent in relation to the procedure and its risks (Gordon et al., 2013). Furthermore, Gordon et al. (2013) discuss the concept of shared decision-making in kidney transplantation, which is a patient-centered discussion. Rather than solely focusing on the procedure and risks, shared decision-making takes a step further by discussing alternative treatment options which considers the specific patient's circumstances including: medical/surgical considerations, social, economic, and demographic considerations (Gordon et al., 2013).

Though participants did not suggest a bigger role or different decisions, their lack of knowledge could point to wider concerns about patient role in decision-making. The shared decision-making model may have been helpful in the cases of Barbara and Richard as they would have been able to share their own perspectives and have a say in their medical treatment plan in combination with more knowledge regarding alternate treatment options and risk. Therefore, my study echoes the findings of Gordon et al. (2013) in relation to what participants wish they would have known.

Patients Strive to Achieve Normalcy and Control in their Lives

Participants in my study talked about the various ways they achieved feelings of normalcy throughout their recovery process. Richard described his recovery as being interwoven through multiple examples of ways his medical team inserted humour in their day to day activities including telling jokes to one another. This allowed him to feel a sense of connection to his medical team and in turn, a sense of normalcy. Richard and Barbara's friends and family also brought them various sweet treats while in hospital. Although it impacted their blood sugar levels, this too allowed for a sense of normalcy in an otherwise uncomfortable setting and new-found control over their diets.

Overall, participants felt a strong sense of connection to their treatment team, particularly their transplant nephrologists, and this was connected to the issue of normalcy. Richard and Robert specifically discussed the ways in which their transplant nephrologist made them feel comfortable and normalized their situations. Robert felt an added layer of ease when his transplant nephrologist spoke to each member of his family in order to give them the most updated information on his condition. He felt the time she spent on his care was admirable and contributed to his recovery.

Another facet of control and normalcy includes returning to the work force. De Pasquale and colleagues (2019) state, "the main goals of kidney transplantation are to recreate a condition of psychophysical well-being and to improve the quality of life of the patient, including going back to work after transplant" (p. 153). During Kyle's interview, he spoke about his limited work experience pre-transplant due to his ongoing medical challenges. Since recovering from transplantation, his goal is to work toward a career. Although research studies consider returning to work to be an indicator for successful transplantation, this can also be viewed using a critical disability lens.

Often, the goal of many transplant recipients is to return to the work force or enter into it. Goodley (2013) describes how people who are deemed to be disabled were traditionally excluded from the work force. Society has engrained the able-bodied dominant view into the minds of the majority, leading transplant recipients down the same path. These are complicated issues because it is hard to separate what the person themselves really values from what society says is normal and acceptable. Supporting Kyle to find employment (or supporting other kinds of "normalcy") is sometimes a very important social work role. Another role can be to support people to find meaning when their lives do not involve social valued "normal" roles like paid work.

The Importance of a Social Support Network

Participants in my study were all very fortunate to have excellent social support networks, and demonstrated the utmost appreciation for their family members and friends during their interviews. Hassan and Robert were married, their spouses were discussed as being their caregivers during the recovery phase. Christine, Kyle, Barbara, and Richard were single, relying on the support of either their parents, children, siblings, or aunts and uncles during the recovery phase. These family members provided various types of support including emotional support, or as Robert explained it, the "rah rah rah" cheerleading type of support. They also provided support for instrumental tasks such as transportation and assistance with heavy lifting including grocery shopping.

My study drew forward similar findings as the work of Been-Dahmen and colleagues (2018) when they discuss the importance of family members listening and paying attention to the emotional responses of transplant recipients and providing them with the opportunity to share their experiences after surgery. Been-Dahmen et al. (2018) also discuss the importance of family assistance with instrumental tasks, which my study echoed as well. Ultimately, the publication of Been-Dahmen et al. (2018) demonstrated a need for a more comprehensive approach to the care of transplant recipients post-operatively, specifically surrounding emotional and social challenges often faced.

The Many Meanings of (and Bumpy Path) to Recovery

Participants in my study all encountered a layer of challenge or time of difficulty during their transplant journey. Specifically, Richard enduring post-operative heart attacks, Robert experiencing post-operative urological challenges, Hassan's home care agency neglecting to follow-up, and Barbara's 'sleeper' kidney. Christine also informed me about her pre-operative chicken pox mishap where she was given the vaccine by error and contracted the chicken pox due to her compromised immune system. Despite the complications endured, participants appeared to recover well with the support of their families and medical teams.

Participants appeared to adjust their views on what recovery meant to them as some struggles continued to persist including Richard's cardiac condition and Barbara's ongoing need for dialysis. Barbara and Robert described how they began to feel better emotionally when their medical issues began to diminish. This finding reflects the work of Penn et al. (1971) who compared depression in transplant patients pre- and post-operatively indicating in those who presented with depression tended to resolve with the resolution of surgical complications (as cited in Beidel, 1987).

My study also reflects the findings of Boaz and Morgan's (2014) research conducted with renal transplant recipients during various points in time along their post-operative journey including three months, one year, and more than three years. At three months, participants experienced a positive shift in their health including the ability to return to work, hobbies, supporting others, holidays, and socializing with food and drink (Boaz & Morgan, 2014). At one year, some participants had experienced rejection while others felt their lives were less dominated by medication and hospital visits (Boaz & Morgan, 2014). Participants in this study were more engaged in everyday life and gained the ability to resume previous hobbies and pursue new interests (Boaz & Morgan, 2014). As with Boaz and Morgan's (2014) study, my participants' idea of normality and returning to health varied amongst participants. Overall, there was an overarching notion that participants discussed, which was, “it gets better,” as Kyle eloquently exclaimed and the sense that the procedure was ultimately, “worth it,” in terms of symptom improvement and overall quality of life.

Implications for Social Work Practice

Social Workers’ Roles in Providing and Facilitating Social Support

Emotional Support

Throughout my interviews, participants alluded to the ways social work interventions have either helped them in the past or ways the interventions can help others. However, few had meaningful dealings with social workers along their journey, at least little was discussed or remembered. Richard was the only participant who appeared to have significant social work involvement throughout his end-stage renal disease journey as he discussed speaking to his social worker in the dialysis unit who eventually visited him in hospital post-transplantation. Richard explained how the emotional support from his social worker allowed the process to run more smoothly because he had a consistent outlet to communicate with during dialysis sessions and post-transplant. Unfortunately, the social work resources at SJHH are siloed because there are different social workers assigned to the inpatient and outpatient setting. In Richard’s particular case, his dialysis social worker went the extra mile to travel to the inpatient site of SJHH to visit him. This is not common practice as the segregated social work roles and caseload demands interfere with this level of continuity.

As previously noted in various research studies, it is important for health care practitioners to understand the mental status of the patients completing the transplant work-up in order to prepare them for surgery (Beidel, 1987). This impacts practice by health care practitioners encouraging patients to bring a family member or friend to all appointments to ensure they are absorbing the information because anxiety could impact their ability to learn. This also demonstrates the importance of recognizing the individual needs of each patient. If health care practitioners are better prepared to engage these individuals with a tailored pre-operative educational approach, it may lead to more positive post-transplant outcomes (Been-Dahmen et al., 2018). My research confirms that attending to the mental health and psychosocial functioning of recipients pre- and post-transplant is essential. Chen et al. (2014) reflect how depressive symptoms are an important predictor of social functioning and how health care professionals must understand recipients' physical and psychosocial problems.

Social workers can also connect individuals with a limited social network to various support groups or provide emotional support themselves. The role of a social worker is imperative in order to support each transplant candidate using a holistic approach. Social workers can aid with the psychological transition from dialysis to transplant and in turn, help individuals overcome the psychosocial and socioeconomic challenges associated with organ transplantation. As the STCS highlights, a biopsychosocial approach to transplantation is essential (De Geest et al., 2013). It is my opinion that social workers possess the skills to spearhead these interventions.

In my role as a psychosocial evaluator, patients who have few social supports and low health literacy are often interviewed. When these cases are discussed with the transplant physician, they often underestimate the impact these psychosocial factors have on patients post-transplant. Rather than deny care to individuals without social supports, we need to look at how to provide them with better supports and connections to community resources prior to transplantation.

Practical Support

Participants in my study expressed awareness of how social workers can intervene to connect individuals with support for completing instrumental tasks. Christine described completing short-term disability paperwork through her employee benefits. She had no challenges completing this independently, however many individuals have difficulty. Kyle shared how his social worker, although a brief encounter, allowed him to feel he could contact them whenever needed. Kyle was aware that if he required assistance working with Ontario Disability Support Program (ODSP) to obtain confirmation of medical transportation, the social worker could help with this. Barbara also shared her knowledge of individuals with limited financial resources or social supports and how social workers can assist by connecting them to financial resources and home care services. Ultimately, participants were somewhat aware of the social work role and what social workers do, alluding to how the social work role could be further integrated into the pre- and post-transplant clinic in a greater capacity. Although participants demonstrated knowledge of the importance of instrumental task coordination, my literature review demonstrated few instances where the significance of this type of support was discussed.

Patient Advocacy

Social workers have the unique ability to integrate patient advocacy into their role. We listen to countless patient stories and advocate through communication to the medical team and various allied health professionals. Through personal experience, I have observed that patients often feel they have not received enough information about their care plan or surgical outcomes. Social workers often inform physicians about these patient requests, allowing for patients to receive additional information about what they are requesting to learn more about.

Social workers also have the ability to view patients in a holistic way, including patients' desire for normalcy. It is not uncommon for social workers to engage in humorous discussion with patients or to grab a coffee for a patient who strives to achieve a glimpse of normalcy while recovering in hospital.

Patients' overall feelings of whether or not receiving a renal transplant is "worth it" appear to be related to their overall quality of life and medical symptoms after surgery. Social workers can aid during this transition through the interventions listed above including supportive counselling and through facilitating community resource coordination. Supportive emotional counselling and referrals to community agencies that provide practical assistance, for example, transportation, can decrease life stressors and contribute to improved quality of life. Having a dedicated social worker in the pre- and post-transplant clinic would ultimately allow these implications for practice to be carried out accordingly.

Restructuring Social Work Interventions

Social workers play an integral role in pre-transplant preparation and education as well as post-transplant emotional and instrumental support. Sas (2019) asserts that the social worker's psychosocial assessment is essential because it focuses on three key aspects: determining a patient's eligibility for a kidney transplant, preserving a scarce resource, and trying to ensure positive outcomes for the patient post-transplant. The lack of dedicated social work staff in the pre-transplant clinic at SJHH contributes to a disjuncture between patients and their overall well-being prior to surgery. For example, social workers can intervene across the various domains including individuals' mental health status, socioeconomic status, and social supports. Social work interventions may include: individual counselling, responding to various kinds of mental health disabilities, or applying to medication coverage programs. My literature review and study confirm the significance of these supports in recovery. Social workers may consider advocating to senior hospital management for funding for enhanced staff allocation in order support the needs of this patient population.

It is important to clarify that I am not advocating for a delay in patients being placed on the transplant waiting list, or denying them this valued resource (as this could contribute to disparities in care). However, I am very aware from my own practice experience, of the adverse outcomes for patients when they do not have resources and supports in place. These adverse outcomes can include suffering, and financial hardship. My analysis points to the need for extended and enhanced social work involvement. The patients in my study recovered well in part because these supports were in place. Enhanced social work can ensure that all patients, and especially those with fewer resources, have equal opportunity to be prepared for and recover well from transplantation. In most cases there is plenty of time to complete this work as patients are often on the waiting list for several years prior to transplantation.

The value of patients being able to tell their stories came forward in the process of my study. There appeared to be a therapeutic element to my interview as participants seemed to enjoy having the opportunity to share the trajectory of their transplant journey from start to finish. An opportunity they would be unlikely to receive if not for participating in my study, further reflecting the importance of participants having the ability to share their story with a social worker. Dwarswaard, Bakker, van Staa, and Boeije (2015) reflect upon the importance of addressing these domains in order to promote effective self-management.

As Richard pointed out, it was helpful for him to have a familiar face who intervened along his journey with end-stage renal disease, allowing for the process to run smoothly. In my personal experience, there have been patients I have completed the pre-transplant assessment with who have gone on to have a renal transplant and interacted with me in the hospital waiting room, recognizing me from our previous interaction. Patients have requested that I follow them while in hospital, despite my role description not including the “Renal Transplant Unit.” Patients have specified they feel more comfortable speaking to someone who is familiar with their story, rather than meeting with a new social worker and having to repeat themselves.

Few instances, depending on my caseload demands, have allowed me to work with these patients post-operatively; which involves completing a second psychosocial assessment, pre- and post-operative counselling, and facilitating discharge by means of coordinating the roles of each professional involved in a patients' care to assure a coordinated care/discharge plan is carried out. Sinding and colleagues (2013) would describe this as going "above and beyond" or doing more than is required by their silo. Sinding et al. (2013) raise an important insight specific to the social work role, which is integrating the assessments from all disciplines into a cohesive whole, in order for care to continue moving forward, specifically related to discharge planning. Sinding et al. (2013) state, "adequate care for people with both mental and physical health needs requires an approach that does not accept the organization of care systems as a given, or as an excuse for substandard patient care" (p. 300). Although the findings of Sinding and colleagues (2013) reflect working with patients who have both mental and physical health needs, the same can be transferred into working with individuals along the end-stage renal disease journey. As previously discussed, patients with end-stage renal disease often have mental health diagnoses and my clinical and research experience have demonstrated the benefits of continuity of care amongst health professionals. Therefore, it appears a more fulsome social work staff compliment in the pre- and post- transplant clinic is indicated.

Limitations

Although the participants in this study provided excellent information about their journey with end-stage renal disease, every research study has its limitations. For my study in particular, the limitations are as follows. There were only six participants in my study, which is a small sample size to be able to generalize from the information obtained. Secondly, all participants had similar demographics, causing a lack of diversity amongst responses. Each participant had excellent social supports, was financially stable, securely housed, and had the ability to function independently with mobility along with basic and instrumental activities of daily living. The individuals in my study reveal the experiences of a relatively privileged and well supported group, ultimately affecting the renal transplant experience.

My research study led me to think about future possibilities of conducting research with renal transplant recipients. It would be helpful to increase the sample size and diversity amongst participants. Perhaps interviewing renal transplant recipients who have a limited social support network, limited finances, and require assistance with activities of daily living would generate different responses and directions for practice. Lastly, another opportunity for future research with the renal transplant population could be with their caregivers; understanding the process from their perspective and what changes they would recommend. These particular research areas would benefit specifically from a critical disability studies perspective because there appears to be a gap in the renal literature regarding this theoretical perspective along with limited attention to the social, political, and economic contexts of the lives and care of renal transplant recipients and their family members.

Concluding Remarks

In conclusion, end-stage renal disease is a chronic illness with multi-faceted treatment options. Several research studies have been conducted within this population to explore aspects of their lives including: living with end-stage renal disease, psychosocial well-being, the importance of social supports, socioeconomic contexts, post-transplant quality of life, and the social work role. This particular single-center study was designed to emphasize the importance of patients as the experts of their experience and to explore the possibilities for enhanced social work support for individuals along the end-stage renal disease treatment trajectory, particularly transplantation. My study allowed the opportunity for participants to share their overall transplant experience and reflected upon the ways they prepared, hopes, experiences, and perspectives of recovery, meanings of recovery, the significance of social and economic supports, and the role of professional staff.

This research reflects the contributions of other researchers by means of demonstrating the importance of social and economic supports along with how individuals view their illness and recovery. It added a new layer of information to the literature which was that participants generally want to know as much information as possible about the potential for medical complications post-operatively and how to care for themselves. Critical disability studies allows us to see more deeply, the ways that participants feel the need to reintegrate into society by means of gaining employment and the notion of normalcy. This research also demonstrated how social workers have the unique ability to aid in one's illness trajectory across the various domains identified and help to overcome the psychosocial and socioeconomic barriers associated with transplantation. Enhancing the pre- and post-transplant social work role at SJHH would be in keeping with commitments many hospitals are making to better address the social determinants of health including both proximal and complex distal components (Craig, Bejan, & Muskat, 2013). Overall, participants in my study paved the way by demonstrating the ways that the social work role could be further integrated in the pre- and post-transplant phase of end-stage renal disease and future research conducted with individuals who have fewer social and economic resources may confirm and extend this knowledge.

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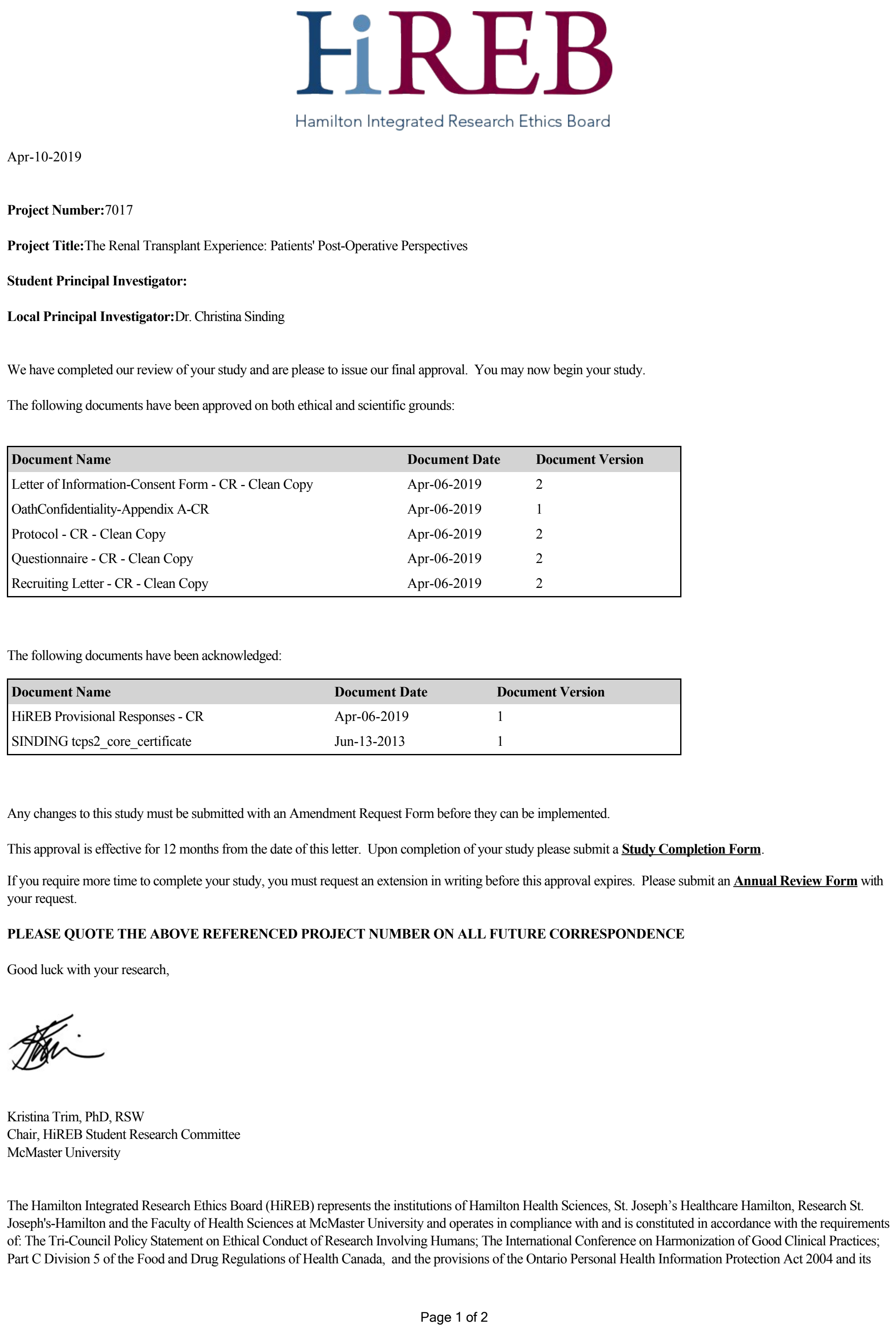
Appendices

Appendix A: Ethics Approval Certificate



HiREB
Hamilton Integrated Research Ethics Board

Apr-10-2019

Project Number:7017

Project Title: The Renal Transplant Experience: Patients' Post-Operative Perspectives

Student Principal Investigator:

Local Principal Investigator: Dr. Christina Sinding

We have completed our review of your study and are please to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Letter of Information-Consent Form - CR - Clean Copy	Apr-06-2019	2
OathConfidentiality-Appendix A-CR	Apr-06-2019	1
Protocol - CR - Clean Copy	Apr-06-2019	2
Questionnaire - CR - Clean Copy	Apr-06-2019	2
Recruiting Letter - CR - Clean Copy	Apr-06-2019	2

The following documents have been acknowledged:

Document Name	Document Date	Document Version
HiREB Provisional Responses - CR	Apr-06-2019	1
SINDING tcps2_core_certificate	Jun-13-2013	1

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a **Study Completion Form**.

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review Form** with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

The Hamilton Integrated Research Ethics Board (HiREB) represents the institutions of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, Research St. Joseph's-Hamilton and the Faculty of Health Sciences at McMaster University and operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its

Page 1 of 2

applicable Regulations; for studies conducted at St. Joseph's Healthcare Hamilton, HIREB complies with the Health Ethics Guide of the Catholic Alliance of Canada

Appendix B: Recruiting Letter

Recruiting Letter

McMaster
University
Inspiring Innovation and Discovery

This information letter about the study will be provided to transplant recipients by:

Dr. Ribic and Dr. Yohanna - Transplant Nephrologists at St. Joseph's Healthcare Hamilton.

Information letter script:

Please review this information letter about a study being conducted by Courtney Rogic toward her Master's thesis in Social Work. Courtney is a Social Worker at St. Joseph's Healthcare Hamilton. I encourage those of you who have received a deceased donor kidney transplant one to six months ago to consider participating. For more information, or to express your interest in the study, please contact Courtney Rogic directly.

Information Letter:

McMaster
University
Inspiring Innovation and Discovery

I am conducting a research study on the experiences of individuals who have had kidney transplants. I would like to gain a better understanding of the perspectives of patients about how they prepared for surgery, if they felt prepared for surgery, what they wish they would have known, and any recommendations for future transplant candidates. I would like to know if patients felt prepared for surgery and how it relates to the social work role.

This study is part of the requirements for my Master of Social Work degree at McMaster University, under the supervision of Dr. Christina Sinding. This study has been reviewed by the Hamilton Integrated Research Ethics Board.

I am looking for volunteers who have had a kidney transplant one to six months ago to participate in a one-time telephone interview with me for 30-45 minutes. **Each participant will receive a $25.00 Amazon gift card.**

Any information that I find out about you that could identify you will not be published or told to anyone else, including members of your care team. Information you provide will be published and/or presented in a way that is non-identifying and only relates to this study. I will make every effort to preserve your confidentiality.

If you are interested in learning more about this study and possibly participating, please e-mail me at rogicc@mcmaster.ca or complete the consent for contact form below, fold it, and place it in the enclosed/confidential **orange box** at the reception desk of the transplant clinic. I will pick up the responses in order to preserve your confidentiality.

Thank you for considering this request. I hope to hear from you soon.

Courtney Rogic, B.A., B.S.W.
M.S.W. Candidate, School of Social Work
McMaster University

Appendix C: Consent for Contact

Consent for Contact

If you think you may be interested in participating in this study, or would like to talk with me about the study before making your decision, I would like your permission to contact you by phone or email. Your decision whether to participate in the study or not will not be shared with anyone in the transplant clinic. In that way your privacy will be respected.

I give permission for Courtney Rogic to contact me regarding my possible involvement in her research study.

She may contact me by phone/ email at ______________________________ .
The best times to reach me are _____________________________________.

Additional Comments (if any)

Name: ________________________Date:__________________________

Appendix D: Letter of Information/Consent

LETTER OF INFORMATION / CONSENT FOR PATIENTS

The Renal Transplant Experience: Patients' Post-Operative Perspectives

Faculty Supervisor
Dr. Christina Sinding
School of Social Work
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext. 22740
E-mail: sinding@mcmaster.ca

Student Investigator
Courtney Rogic
School of Social Work
McMaster University
Hamilton, Ontario, Canada
(905) 522-1155 ext. 33931
E-mail: rogicc@mcmaster.ca

Purpose of the Study:

You are invited to participate in a research study conducted by Courtney Rogic on the post-operative experiences of kidney transplant recipients. This is a student research project conducted under the supervision of Dr. Christina Sinding.

My name is Courtney Rogic and I am a Master of Social Work candidate presently enrolled at McMaster University. I am in the process of completing the thesis requirement of the program. I am a social worker employed in the pre-transplant clinic at St. Joseph's Healthcare Hamilton but will not be working there at the time of the study. The purpose of my study is to gain a better understanding of the perspectives of individuals who have had kidney transplants (one to six months ago) and learn about their experience before and after surgery. I would like to know if patients felt prepared for surgery and how it relates to the social work role.

Procedures Involved in the Research:

I would like to invite you to participate in a 30-45 minute telephone interview where you will be asked questions about your experiences before and after receiving a kidney transplant. I am interested in learning about how you prepared for surgery and recommendations you may have for transplant clinic staff on how we can prepare transplant patients in the future. With your permission, the interview will be audio recorded and transcribed. I will be interviewing 10-15 individuals for this study and will be hiring someone to transcribe the interviews. Your responses will be kept confidential by the hired transcriptionist who will sign a confidentiality agreement form.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. You may feel uncomfortable with describing your experiences or you may find it stressful to remember an unpleasant part of your recovery. You might worry that a negative response will impact your care in the future or that your answers will be traced back to you. If you feel you might benefit from supportive counselling, I will refer you to the transplant clinic social worker with your consent.

In order to avoid the risks of having a dual role, I will only interview people who do not receive social work services from me. I am not presently working in the Kidney and Urinary program. Upon my return to the Kidney and Urinary program next year, I will be working in the Nephrology unit. If you are admitted to the Nephrology unit, I ask one of my colleagues to provide care for you – this is a common practice, and no one will be told that you were a participant in my study.

I will take precaution to ensure the confidentiality of all information that you provide. You do not need to answer any questions that make you feel uncomfortable or that you do not wish to answer.

When reporting the findings, every effort will be made to preserve your confidentiality. The information I collect about you (such as age, gender, who you live with, and relationship status) will be used only to describe the participant group. This information will not be linked to any quotes of yours that I may use. However, considering the that only about 100 transplant surgeries are completed each year, you may be identified by the answers you provide. Please keep this in mind when deciding what to say.

You can withdraw from the study at any time until July 1, 2019 without consequence.

Potential Benefits:

It is my hope that through participation in this study you will be given the opportunity to share your experience with receiving a kidney transplant. I hope that the information you share will help transplant clinic staff learn how to better educate and prepare future kidney transplant recipients.

Payment or Reimbursement:

You will be provided with a $25.00 Amazon gift certificate as a token of appreciation and compensation for your time.

Confidentiality:

I want to assure you that confidentiality is very important. Every precaution will be taken to preserve your identity. Any information that I find out about you that could identify you will not be published or told to anyone else, including members of your care team. Information you provide will be published and/or presented in a way that is non-identifying and only relates to this study.

The information obtained by me will be kept on my person or in a locked file cabinet. It will only be available to my academic supervisor and me. The computer that I will be using is my personal computer which is password protected. Upon successful defense of my thesis, the information you provide will be shredded, and audiotapes will be destroyed.

b) Legally Required Disclosure:
i) Although I will protect your privacy as outlined above, if the law or my professional obligations requires it, I will have to reveal certain personal information (e.g., suicidal thoughts).

Participation and Withdrawal:

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can stop (withdraw), from the interview for whatever reason, even after signing the consent form or up until July 1, 2019 when I expect to be writing my research findings for my thesis. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results:

I expect to have this study completed by September 2019. If you would like a brief summary of the results, please let me know how you would like it sent to you. You can contact me by e-mail that has been provided.

Questions about the Study: If you have questions or need more information about the study itself, please contact me at:

rogicc@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a

research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Courtney Rogic, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until July 1, 2019. I have been given a signed copy of this form and agree to participate in this study.

Signature: ______________________________________ Date:
____

Name of Participant (Printed) ___________________________________

1. I agree that the interview can be audio recorded.
[ ] Yes
[ ] No

2. [ ] Yes, I would like to receive a summary of the study's results.
Please send them to me at this email address
____
Or to this mailing address:
____

____

____
[ ] No, I do not want to receive a summary of the study's results.

3. I agree to be contacted about a follow-up interview, and understand that I can always decline the request.
[ ] Yes, please contact me at:
____
[ ] No

Appendix E: Questionnaire

McMaster
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Inspiring Innovation and Discovery

Post-Transplant Qualitative Study Questionnaire
Courtney Rogic

Pre-transplant:

1. I want to take you back to the time when you were undergoing the various tests for surgery. What do you remember about that time?

2. What was your greatest worry?

3. How did you prepare yourself? *(i.e. emotionally, post-operative care needs, financially)*

Post-transplant:

4. What was the most difficult part of your recovery?

5. Looking back now, is there anything that could have eased the difficult parts? *[probe for what this could have looked like, who would have been involved/where they'd have wanted support from, etc.]*

6. What do you wish you would have known, or known more about prior to surgery?

7. What kinds of emotional support did you receive? What kinds from family/friends, social workers, physician, nurses?
    a. *Did you feel it was sufficient?*

8. What kinds of support did you receive with practical tasks? *(i.e. assistance applying for medication coverage if needed, planning for post-operative care, applying to E.I. or short-term disability through your employer if needed)*
    a. *Did you feel it was sufficient?*

9. What advice would you give to someone else like you in a similar situation who had this surgery upcoming?

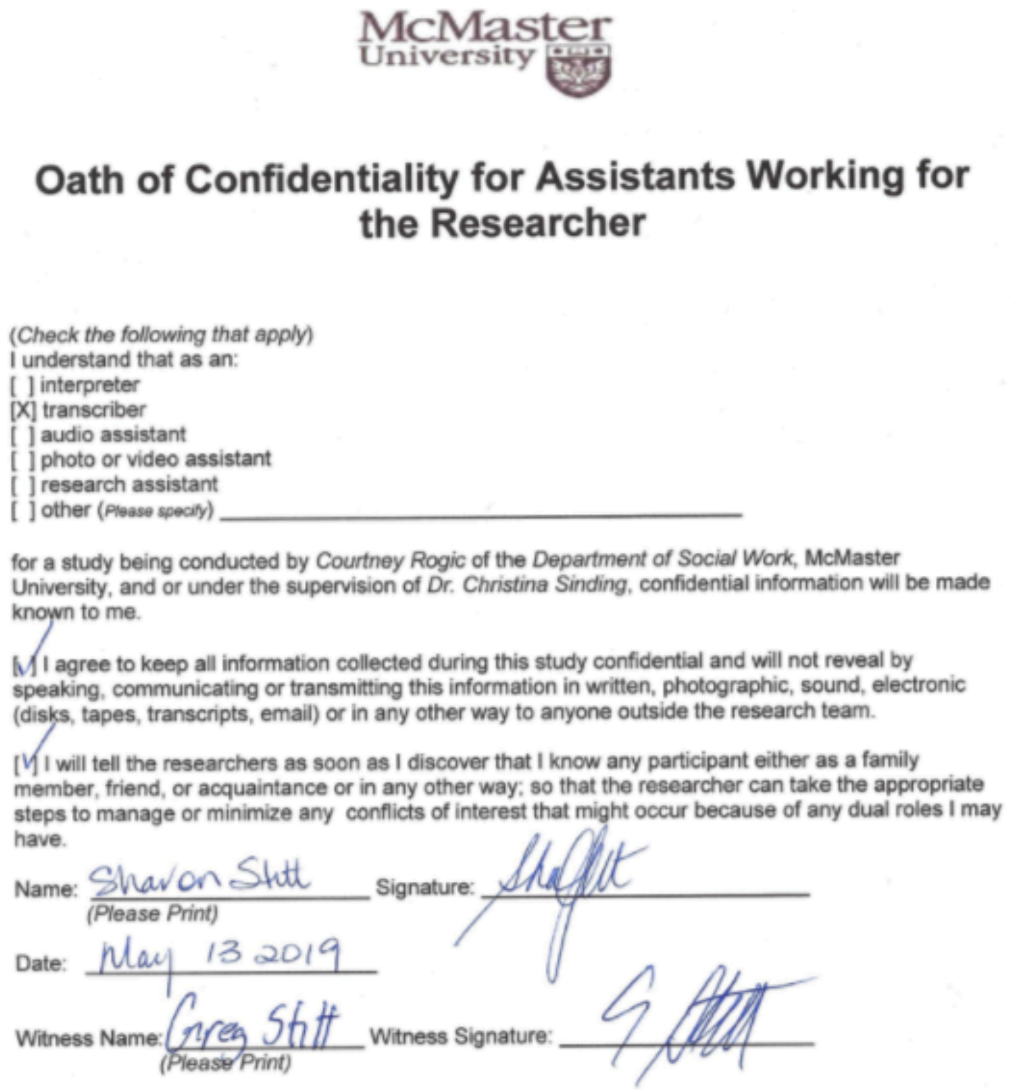
Improvement of service delivery:

10. Do you have any recommendations for social work staff on how we could improve the transplant patient experience?

Demographics (if not brought up during discussion):

11. Year of birth/approximate age
12. Preferred gender
13. Employment status
14. Relationship status
15. Who lives in your household/proximity of adult children and other potential supporters

Appendix F: Oath of Confidentiality (Transcriptionist)



McMaster
University

Oath of Confidentiality for Assistants Working for the Researcher

(*Check the following that apply*)
I understand that as an:
[ ] interpreter
[X] transcriber
[ ] audio assistant
[ ] photo or video assistant
[ ] research assistant
[ ] other (*Please specify*) ______________________

for a study being conducted by *Courtney Rogic* of the *Department of Social Work*, McMaster University, and or under the supervision of *Dr. Christina Sinding*, confidential information will be made known to me.

[✓] I agree to keep all information collected during this study confidential and will not reveal by speaking, communicating or transmitting this information in written, photographic, sound, electronic (disks, tapes, transcripts, email) or in any other way to anyone outside the research team.

[✓] I will tell the researchers as soon as I discover that I know any participant either as a family member, friend, or acquaintance or in any other way; so that the researcher can take the appropriate steps to manage or minimize any conflicts of interest that might occur because of any dual roles I may have.

Name: Sharon Stitt Signature: ____________
(*Please Print*)

Date: May 13 2019

Witness Name: Greg Stitt Witness Signature: ____________
(*Please Print*)