

WAITING FOR A LIVER TRANSPLANT: AN EXPLORATION OF THE LIVED  
EXPERIENCE OF PATIENTS AND CAREGIVERS IN ATLANTIC CANADA

by

Bridget Anne Pierce

Submitted in partial fulfilment of the requirements  
for the degree of Master of Nursing

at

Dalhousie University  
Halifax, Nova Scotia  
October 2014

© Copyright by Bridget Anne Pierce, 2014

## DEDICATION PAGE

It brings me great delight to thank all of those who have made the completion of this thesis possible. First, I would like to thank my supervisor Dr. Brenda Sabo. Dr. Sabo supported me throughout this journey with endless guidance, patience, mentorship and confidence.

I would also like to thank my thesis committee, whose diverse background brought many different perspectives to my dissertation and thinking. Dr. Andrea Chircop for bringing her expertise on qualitative methodology and health equity, Dr. Lynette Reid for sharing her knowledge of bioethics and marginalized populations and Victoria Sullivan for lending a clinical lens as a skilled administrator and practitioner.

The recruitment of my participants would not be possible without the staff of the Atlantic Multi Organ Transplant Program of Capital Health: Dr. Kevork Peltekian, Catherine and Mary-Jane. In particular, I would like to thank Catherine for her dedication, persistence and for sharing her expertise on this population with me. This link to the Transplant Program would not have been possible without the commitment of the staff, and for that I am thankful.

Crucial to this study, I would like to thank my seven participants who opened up their deepest thoughts, fears, hopes and experiences with me. I feel privileged to have had the opportunity to learn from you and to share your stories with the transplant and nursing communities.

I would also like to acknowledge and thank the Capital Health Research Fund for so graciously funding this Masters' thesis study. This support was greatly appreciated and allowed me to conduct this work without significant financial constraints.

Most importantly, I would like to extend my heartfelt thanks to my family who have encouraged me throughout the way. My mother, Joan has served as the most influential person to my work and life, even when pretending she knew what I was talking about when teasing out the directions of my dissertation. Thank you to my entire family, especially TC and LC. Lastly, to Ryan - thank you for your patience, love and encouragement throughout this entire process. I could not have done this without the support of my loved ones, and I am eternally grateful for this.

## Table of Contents

<b>List of Tables .....</b>	<b>vii</b>
<b>List of Figures.....</b>	<b>viii</b>
<b>Abstract.....</b>	<b>ix</b>
<b>Chapter 1 Introduction.....</b>	<b>1</b>
1.1 Identifying The Problem .....	1
1.1.2 Psychological Aspect Of Liver Disease.....	5
1.2 Locating Myself In The Research.....	7
1.3 Purpose.....	11
1.4 Significance Of This Research.....	11
<b>Chapter 2 Literature Review .....</b>	<b>13</b>
2.1 Waiting.....	15
2.2 Waiting For A Liver Transplant .....	18
2.3 Quality of Life.....	26
2.4 Psychological Distress .....	26
2.5 Moral Distress.....	27
2.6 Mental Rollercoaster .....	29
2.7 Moral Distress.....	27
2.8 Sociocultural Context Of Illness .....	34
2.9 Stigma .....	35
2.10 Healthcare Providers' Attitudes And Beliefs.....	38
2.11 The Experience of Waiting Among Spouses and Family Members.....	39
2.12 In Summary.....	43
<b>Chapter 3 Paradigm, Methodology &amp; Analysis .....</b>	<b>45</b>
3.1 Research Paradigm: Interpretive Phenomenology .....	45
3.2 Theoretical Framework.....	49
3.2.1 Family Resiliency Theory .....	49
3.2.2 Uncertainty in Illness Theory.....	53
3.2.3 Phenomenology, Resilience Theory And Uncertainty.....	56

3.3 Study Method.....	58
3.3.1 Setting .....	58
3.3.2 Sample.....	59
3.3.3 Sample Size.....	60
3.3.4 Sampling Technique .....	61
3.3.5 Data Collection .....	63
3.3.6 Data Analysis .....	65
3.4 Establishing Rigor & Trustworthiness .....	70
3.5 Ethical Considerations .....	73
3.5.1 Consent Process / Recruitment. ....	73
3.5.2 Privacy & Confidentiality .....	75
3.6 In Summary.....	77
<b>Chapter 4 Waiting For A Liver Transplant .....</b>	<b>78</b>
4.1 Participants.....	78
4.2 Introducing The Findings.....	80
<b>Chapter 5 The Patient Experience.....</b>	<b>83</b>
5.1 Introduction.....	83
5.2 Waiting For The Phone Call .....	83
5.2.1 Waiting: The Hardest Part .....	84
5.2.2 Paradox Of The Ring – A Double Edged Sword.....	87
5.2.3 In Summary.....	88
5.3 Light At The End Of The Tunnel .....	89
5.3.1 Getting on with our lives .....	90
5.3.2 The Need For Support.....	93
5.3.3 In Summary.....	101
5.4 Riding The Emotional Roller Coaster Of Waiting .....	101
5.4.1 The Donor: The Ethics Of Goodbye .....	103
5.4.2 The Transplant Team .....	105
5.4.3 In Summary.....	106
5.5 Negotiating The Disruption: Redefining Self .....	107

5.5.1 Loss: Images Of Self.....	107
5.5.2 How Things Have Changed .....	109
5.5.3 Loss Of Self - Physical Limitations .....	111
5.5.4 What Matters Now .....	118
5.5.5 Living Day By Day .....	119
5.5.6 In Summary .....	121
<b>Chapter 6 The Caregiver Experience.....</b>	<b>122</b>
6.1 Introduction.....	122
6.2 Waiting For The Phone Call .....	122
6.2.1 Tied To The Phone.....	123
6.2.2 A Family in Waiting - The Right Time .....	125
6.2.3 In Summary .....	128
6.3 Negotiating The Disruption: Redefining Self .....	128
6.3.1 Caregiving; Not Optional.....	130
6.3.2 The Need For Hope.....	139
6.3.3 What Matters Now .....	144
6.3.4 In Summary .....	145
6.4 Light At The End Of The Tunnel .....	145
6.4.1 Support Outside Of The Home .....	148
6.4.2 In Summary .....	154
6.5 Riding The Emotional Roller Coaster Of Waiting .....	155
6.5.1 The What Ifs: Thinking The Worst.....	155
6.5.2 Transplantation; A Source Of Life And Loss .....	159
6.5.3 Fear And Worry: No Escape .....	164
6.5.4 Self-Care: An Afterthought.....	169
6.5.5 In Summary .....	171
<b>Chapter 7 Discussion.....</b>	<b>172</b>
7.1 Introduction.....	172
7.2 Conundrum Of Hope.....	175
7.3 Waiting For The Phone Call .....	182

7.4 Negotiating The Disruption: Redefining Self .....	186
7.5 Light At The End Of The Tunnel .....	198
7.6 Riding The Emotional Roller Coaster Of Waiting .....	205
7.7 In Summary.....	218
<b>Chapter 8 Conclusion .....</b>	<b>219</b>
8.1 Moving Beyond The Findings .....	219
8.2 Study Strengths And Limitations.....	220
8.3 Relevance Of Study Findings .....	224
8.3.1 Practice, Education And Research Implications .....	224
8.4 Final Thoughts .....	229
<b>References.....</b>	<b>231</b>
<b>Appendix A Letter of Invitation .....</b>	<b>251</b>
<b>Appendix B Study Advertisement .....</b>	<b>252</b>
<b>Appendix C Informed Consent.....</b>	<b>253</b>
<b>Appendix D Telephone Consent .....</b>	<b>260</b>
<b>Appendix E Demographic Information Tool .....</b>	<b>262</b>
<b>Appendix F Interview Guide.....</b>	<b>264</b>

## **List of Tables**

Table 4.1	Patient Participants.....	80
Table 4.2	Caregiver Participants.....	80

## List Of Figures

Figure 4.1	Waiting for a Liver Transplant.....	82
------------	-------------------------------------	----



## **Abstract**

Liver transplantation is the only life-sustaining treatment available for patients with end stage liver disease, however the demand for these organs far exceeds availability. Many psychological, emotional and physical symptoms accompany the wait for a liver transplant. An interpretive phenomenological design was used to explore how patients and caregivers experience waiting for a liver transplant. Seven participants were recruited to take part in semi-structured interviews. Findings revealed that patients and caregivers have an overarching experience of the *conundrum of hope*. Four core themes were uncovered: Waiting for the Phone Call, Negotiating the Disruption: Redefining Self, Riding the Emotional Roller Coaster of Waiting and The Light at the End of the Tunnel. Findings of this study identify the need for additional psychological supports to be offered to patients and families, enhanced communication between patients and health care providers and the creation of support communities for both patients and caregivers.

## **Chapter 1 Introduction**

Of the 78 organs that make up the human body, the liver is the largest internal and most metabolically complex organ. Liver disease can be acute or chronic, and is estimated to affect 1 in 10 Canadians in their lifetime (Canadian Liver Foundation, 2013). Many of these liver diseases can lead to end stage liver failure, necessitating a liver transplantation to manage the disease. Individuals requiring liver transplantation can experience a significant wait due to a variety of factors, and during this time they are faced with a myriad of psychological, emotional and physical symptoms that impact upon their day-to-day living. This array of symptoms not only impacts upon the individual requiring transplant, but upon their entire family and caregivers.

### **1.1 Identifying The Problem**

Liver transplantation has not only become a reality for patients living with end stage liver failure; it is the only life-sustaining treatment available for these patients. Over 400 liver transplants are performed each year in Canada (Canadian Liver Foundation, 2013), with liver transplantation remaining the only option for survival of end stage liver disease. Currently the need for this organ far exceeds availability (Stilley et al., 2010). The inadequate supply of organs is a leading contributor to the 5,000 deaths that occur each year in Canada from liver disease (Canadian Liver Foundation, 2013). Currently, one third of patients listed for transplant dying before receiving one (Canadian Liver Foundation, 2013). Less than one percent of the total number of individuals who die become eligible for organ donation (BC Transplant, 2014), therefore individuals awaiting liver transplantation may experience significant wait periods from time of placement on the waiting list to time of transplantation. The

leading cause of liver disease requiring transplantation is hepatitis C; however an unsympathetic stereotype exists among much of society that the majority of individuals with liver disease have “brought this on themselves” as a result of alcoholism or drug addiction. This is of great concern, as this stigma has a significant impact on the psychological and physical health of those who experience liver disease. Regardless of diagnosis leading to liver transplant, a multitude of psychological, emotional and physical symptoms accompany the wait for a liver transplant for the individual their family and their caregivers.

#### 1.1.1 Biomedical Aspect Of Liver Disease

The liver serves as one of the vital organs, performing over 500 functions; including warding off infection, controlling blood sugar, neutralizing toxins and manufacturing proteins and hormones (Canadian Liver Foundation, 2013). Although the liver is the only organ that can regenerate itself making living donor donation medically possible (Canadian Liver Foundation, 2013), these procedures have yet to occur in Atlantic Canada. As a result, liver donation after brain death is the only viable option for individuals awaiting liver transplant in Atlantic Canada. Since less than one percent of all deaths result in brain death, only a very small number of livers are available to meet the significant demand. Brain death is defined as the complete loss of all function in the brain and brain stem, including apnea, loss of consciousness, unresponsive state, absent gag reflex, cough, oculovestibular and oculocephalic reflexes, as well as an unresponsiveness to cranial nerve function (Arbour, 2012). Simply put, brain death is the irreversible cessation of all brain and brain stem functioning, resulting in cardiac death and complete organ failure, if the

individual is not placed on a mechanical ventilator. The most common disease etiologies leading to brain death are traumatic brain injuries, intracranial hemorrhages, hypoxia and primary metastasizing brain tumors.

In 2012, 20 liver transplants were performed in Halifax, Nova Scotia for all individuals living in Atlantic Canada (Nova Scotia, New Brunswick, Prince Edward Island and Newfoundland and Labrador) (MOTP, 2013). While this number may seem small, at any given time there are 15 individuals awaiting liver transplantation in Atlantic Canada. The impact on the Canadian healthcare system has the potential to be great if one considers their frequent interaction with healthcare professionals, treatment costs, hospitalizations for disease-related problems and psychosocial impact (e.g., depression, anxiety).

The cost of providing health care for patients with end stage liver disease in Canada places a significant burden on the healthcare system even before one takes into account the role of family caregivers. The annual cost of treating an individual with liver cirrhosis is approximately \$11,000 (Gagnon, Levy, Iloeke & Briggs, 2004); the cost of treating a patient with hepatitis B is between \$7,000-9,000, while the monthly medication costs for hepatocellular carcinoma are over \$6,000 per month (Canadian Liver Foundation, 2013). These costs are significant; if hepatitis is diagnosed and treated medically before cirrhosis occurs, life expectancy rates remain unchanged (Veldt, Heathcote, Wedemeyer et al., 2007). For individuals awaiting liver transplantation, these cumulative costs often place a financial burden on the patient and family. The average cost for a liver transplant exceeds \$100,000, excluding the ongoing costs for medical treatment and medications post-transplantation (Gagnon,

Levy, Iloeke & Briggs, 2004, Canadian Liver Foundation, 2013).

Although the number of liver transplants done in Atlantic Canada last year is small, the cost of liver transplants alone amounted to over \$2,000,000 last year. This two million dollar estimate accounts solely for the transplantation and in-hospital stay post-transplant, and does not account for the pre-transplant or post-transplant health care costs. Furthermore, these costs are mere estimates, while the hidden costs such as informal caregiver time, lost wages, out of pocket medical expenditures, medications, lodging, travel, and psychological services amongst countless other costs remain unaccounted for. Care provided by family caregivers account for 80 percent of the care that individuals with long-term, chronic conditions require, and it is estimated to contribute more than \$5 billion of unpaid labour annually to the health care system (Fast, Niehaus, Fales & Keating, 2002).

The wait time for a liver transplant depends on many factors including the patient's blood type, size, health status, length of time on the waiting list and availability of a healthy donor liver. In Atlantic Canada, patients with blood group O can expect to wait 2-3 years, patients with blood group A or B 1-2 years and patients with blood group AB 6 months- 1 year. More specifically, patients diagnosed with end stage liver disease are classified using the Model for End Stage Liver Disease, often referred to as the MELD score. This scoring system was first created in 2001 by researchers at the Mayo Clinic, and uses a numerical scale to rank patients need for a liver transplant within the next three months by using a patient's laboratory values for bilirubin, INR and creatinine. These scores may range from 6 to 40, with 40 signifying a critically ill patient. A patient's model for end stage liver disease score

can fluctuate with variations in their overall health. An exacerbation of their disease and declining physical status would be reflected in an increased score. Although there are exceptions to this scoring, such as a higher ranking for hospitalized patients, or those with hepatocellular carcinoma (liver cancer), the model for end stage liver disease score serves as an objective quantifiable ranking system for individuals awaiting liver transplant.

### 1.1.2 Psychological Aspect Of Liver Disease

It would not be improbable to describe the waiting period for a liver transplant as both a mental and physical rollercoaster, with symptoms and emotions ranging across the spectrum from positive to negative. To date, research has focused primarily on the medical, quantifiable aspects of liver transplantation such as wait times, model for end stage liver disease scores, physical symptoms and measurable aspects of post transplant quality of life (Blanch et al., 2004, Caccamo et al., 2001). Only a small amount of research focuses on the lived experience of individuals awaiting organ transplant; with even fewer studies have exploring how individuals and their families live out the time spent waiting for a liver transplant, its meaning and psychosocial effects (Brown et al., 2006). One might assume that the lack of qualitative research focused on the emotional and psychological aspect of how patients experience this time is a result of the predominantly biomedical model used within the Canada healthcare system which places greater emphasis on objective, measurable factors (e.g., symptoms laboratory values, time to transplant, disease relapse), than on the person-centered experience.

Individuals with end stage liver disease awaiting liver transplantation often

experience stigma. Stigma can be defined as the “co-occurrence of labeling, stereotyping, separation, status loss and discrimination in a context in which power is exercised” (Hatzenbuehler, Phelan, & Link, 2013, p. 1). This stigma may stem from the harsh and often misperceived societal assumption that these individuals have brought this upon themselves through excessive alcohol use, illegal drug use or other risky behaviors such as promiscuous sexual activity. Such misguided or ill-informed assumptions leading to stigma may be factors increasing the level of stress associated with illness. In turn, the impact on physical, psychological, emotional and spiritual health adversely impacts the quality of life for both patient and family (Fife & Wright, 2000) who may have already been marginalized, and disenfranchised.

The purpose of this study was to enhance our understanding of how and in what way individuals and their families awaiting liver transplantation live out and assign meaning to this phenomenon in Atlantic Canada. The lack of literature and understanding of the embodied experience of waiting for patients and caregivers awaiting liver transplant as identified in Chapter two helped to inform my decision to focus on the experience of waiting. Although this research study could have focused on the stigmatization of liver disease or other psychological issues related to waiting for liver transplant, the lack of literature on waiting served to reinforce the need and purpose for this study. It must be noted that patients and caregivers not only wait for a suitable transplant, but also for a diagnosis, transplant plan, appointments and to be placed on the waiting list, making this wait multi-faceted and complex. Knowledge gained from this research study has the potential to inform care provided in both the acute care and community setting, where these individuals and their families have

frequent contact with healthcare professionals. Furthermore, knowledge from such a study may be used to improve education, improve existing practices and interventions used by nurses, physicians, psychologists, and social workers. This could lead to more effective healthcare delivery that would be tailored to the specific identified needs of the patient and caregiver, with the potential to lead to an improved quality of life for patients and their families awaiting liver transplantation. Although the symptoms and laboratory values of these patients are imperative to treatment, the psychological, psychosocial, emotional and mental experience of these patients may be left unaddressed or neglected, which could further compromise the health of both patient and family members. Evidence of this can be seen in the significant medical work-up for patients being listed on the liver transplant waitlist in Atlantic Canada, as there are over ten invasive, significant physical medical tests (e.g., echocardiograms, blood testing, CT scans, x-rays, electrocardiograms) for patients being listed, yet only one psychologist visit with a transplant psychologist (MOTP, 2013). Although important, we must not lose sight of the psychological and emotional aspects of patient care for patients, caregivers and families.

## **1.2 Locating Myself In The Research**

While working as a student nurse in the Intensive Care Unit, I had the opportunity to work with both patients and families who had suffered devastating brain injuries. Families and next of kin were approached for permission to have their family member assessed as a possible organ donor. During this time I observed the pain, sorrow and grief these families experienced, and how they rationalized the selfless act of organ donation not infrequently citing how a donation would benefit



another, while serving to honor the legacy of their loved one. I observed how these families came to the decision to have the brain dead family member donate organs. It was during my time in the ICU that I began to wonder how and in what way family members experienced waiting for an organ donation. I have continued to reflect on this issue even as my career shifted to the Perioperative setting. I currently work as a member of the organ retrieval surgical team. Each organ retrieval triggered thoughts of who was the recipient, and how this would impact their life and that of their families. It was also during the times where complete retrieval was not possible that I questioned how these patients, who were undoubtedly called to receive their new life-saving organ, coped with the news that they would not be receiving an organ. I questioned how they coped with the rollercoaster of emotions as they shifted from the anticipation of a transplant to a return to waiting after the “false alarm”.

My experiences and interest in organ donation and transplantation led me to spend my first Master of Nursing clinical day at the pre-liver transplant clinic within the Multi Organ Transplant Program in Halifax. I had the opportunity to meet several patients undergoing assessments for a liver transplant only to discover how many patients and their families on the waiting list experienced intense emotional and mental distress on a daily basis, as they attempted to cope with limited resources and supports. Patients spoke of being “tired of waiting” and “unsure of what to do next”. Factors that may have contributed to their feelings included: 1) the lengthy wait times; 2) the isolation, particularly as liver transplants for Atlantic Canadians only take place in Halifax, Nova Scotia; and, 3) few, or no resources available to assist them during the waiting period. This distress may be compounded by the fact that

these individuals come to Halifax, Nova Scotia to the Transplant Center during their extensive work-up, which includes both physical and psychological assessments. Following an extensive week of assessments, including a separate psychological assessment of the patient and the family, these patients return home to their respective communities with follow-ups by a hepatologist once every three months. Unless requested, there are no formal psychological services for patients and their families, apart from those offered by the pre-liver transplant coordinator nurse. It is not surprising that the lack of resources and deterioration in overall health and quality of life, leave these patients and their families in a state of psychological, emotional and mental turmoil.

Illness has been described as being a “family affair” (Wright & Bell, 2009) forcing families to shift their individual and family routines (Eggenberger, Meisers, Krumwiede, Bliesmer & Earle, 2011). Furthermore, it has been identified that patients and families experience illness as one emotional unit; and any psychological distress in the patient will adversely impact the entire family (Sabo, 2013). Given that individuals awaiting liver transplantation experience their illness and wait within the larger context of their family, it is imperative that research examine both the individual and family experience of awaiting liver transplantation, given that many family members are the primary caregiver for the patient. Understanding the family caregiving experience is essential, as the role of caregiver has the potential to adversely affect the social, physical and psychological well-being of the caregiver as well as the patient (Butterworth, Pymont, Rodgers, Windsor, & Anstey, 2010, Pinquart & Sorensen, 2003, Sabo, 2013).

Research has shown that consideration of family practices are especially important when families face a chronic or life altering/limiting illness. The illness is often associated with complex adaptations and changes in daily routines such as medication regimes, diet changes and self-testing (Rosland, Heisler & Piette, 2012). This remains true for individuals and their families with end-stage liver disease, as both the patient and family find themselves having to cope with a myriad of physical and psychosocial life changes. Life changes for the patient can include frequent health care visits, invasive medical tests, dietary changes, lifestyle modifications (e.g., decreasing alcohol consumption) and an inability to travel and a decrease in energy levels. (Rosland, Heisler & Piette, 2012). Furthermore, families may face role changes (Casida, 2005), financial hardship for the patient, family and caregiver (particularly if the patient was the major source of family income) (Gagnon, Levy, Iloeke & Briggs, 2004, Canadian Liver Foundation, 2013)., increased social isolation and risk for caregiver burnout (Kurz & Cavanugh, 2001, Saxe-Braithwaite & Chapman, 1992). Further identifying how the individual and family members experience end stage liver disease in the larger family context, may provide health care providers with the insight on how to provide more effective, quality, comprehensive family-centered care.

These experiences made me ponder how patients and their families live out waiting for a transplant. I began to question what additional services and resources were needed to more effectively support patients and families during this time. I was left with several unanswered questions, which formed the basis for this research study. I was left wondering how these patients and their families experience this wait

for a liver transplant and how this wait impacts upon the family and couple relationship. When the questions are considered within the context of the literature review that follows, I was able to formulate the research questions and purpose of this qualitative research study.

### **1.3 Purpose**

The purpose of this exploratory interpretive phenomenological study was to understand how patients and their caregivers live out and assign meaning to the experience of waiting for a liver transplant. These findings may help illuminate the poorly understood phenomenon of waiting, through an examination of the following research questions:

1. How do patients experience waiting for a liver transplant?
2. How does the caregiver experience waiting for a liver transplant?

Interviews were held with both the individual awaiting liver transplantation, and their caregiver within an interpretative phenomenological approach, as they are helpful in gaining an understanding of how these individuals experience this complex experience.

### **1.4 Significance Of This Research**

Given that existing research literature on liver transplantation is mainly quantitative in nature, a significant gap was noted, leaving the individual and family lived experience largely unaccounted for. This gap may serve as a barrier to understanding how patients and their families experience waiting for a liver transplant, as well as what resources and supports are necessary for holistic, comprehensive patient and family centered services. It is noteworthy that the research

literature fails to reflect how and in what way waiting for a liver transplantation impacts the life of the patient and their caregivers, considering that waiting may be viewed as a period of complex emotional, physical and mental turmoil. The knowledge gained from this qualitative research study may have the potential to inform education, as well as enhance psychological services and programs, through increased psychological and mental health services for this population. Furthermore, integrating more effective patient/family driven recommendations for support based on needs has the potential to decrease or ameliorate the psychosocial distress associated with an already disenfranchised population.

## Chapter 2 Literature Review

The word wait is both a verb and a noun. In its simplest form wait is defined as a stay where one is, or a delay in action until a particular time or event (Oxford University, 2013). An unknown author described waiting as,

“To wait. We wait as traffic lights turn red and green in rush hour traffic. We wait for an anticipated letter, or for the birth of a child, and though we often sit still while we wait, the act of waiting is never static. Etymologically, wait comes from the French, waiter or to watch and remain in some place”-(wait, n.d.) from Caine & Estefan, 2011.

These insights into the meaning of the word wait help to situate the meaning of waiting for a liver transplant by the patient and their family. Although the “clock time” of waiting for their liver transplant can significantly vary from individual to individual, a period of waiting for transplant is an inevitable reality for families and patients with a diagnosis of end stage liver disease. In Atlantic Canada, the average wait for a liver transplant is dependent on several factors. These factors include the patient’s blood type, size and MELD score (model for end stage liver disease). For example, in Atlantic Canada patients with blood group O can expect to wait 2-3 years, blood group A or B 1-2 years and blood group AB 6 months- 1 year. Although these numeric values are essential to know and appreciate, how these patients and their families live out these days, weeks, months or even years, can offer us valuable insight into the complex experience of waiting for a liver transplant.

True to the Oxford Dictionary definition, patients awaiting a transplant must remain in a state of delayed action, where they wait, hopeful, for their liver transplant.

With their lives on hold, patients and their families have no control over when a suitable liver will be available, regardless of changes and deteriorations in their health status. Understanding of the psychosocial and ethical implications during this period of waiting is limited, particularly as it applies to families, with few studies focused on this aspect of waiting. The literature review that follows will highlight existing knowledge and understanding of the experience of waiting for a liver transplant for both patient and family.

An extensive search of CINAHL, PubMed, PsychInfo, ProQuest Dissertations and Thesis, Social Sciences and Ebsco Host utilizing keyword such as “waiting and liver transplant”, “waiting for liver transplant” and “wait for liver transplant” only revealed 4 studies that focused on the lived experience of patients and/or families waiting for a liver transplant. This alone, underscores the need for further research exploring how and in what way the experience of waiting is lived out by both the patient and family within the context of liver disease.

Similar to other phenomena experienced in ones life, patients and their families awaiting liver transplant experience this period individually with numerous themes identified in the literature. These themes include waiting, living on hold (MacDonald, 2006), feeling confined and restricted (Baker & McWilliam, 2003), searching, coping and the paradox of time (Brown, Sorrell, McClaren & Creswell, 2006). Despite suggestions of the psychosocial implications of waiting within the context of liver transplantation, little is known about the experiences of individuals after liver transplant (e.g., fear of organ rejection, changes in quality of life), and even less is known about the experience before liver transplant (Wainwright, 1997). Much

of the available literature on “waiting” is quantitative in nature; focusing on waiting times, in particular surgical, cancer treatment or emergency room wait times.

Although quantitative research data on the number of days or time spent waiting is imperative, it does not help uncover how the patient and family experience this period of their lives. This qualitative research study seeks to uncover embodied time as it is lived out within the context of waiting for a liver transplant. Similar to other life-limiting illnesses such as cancer and other organ transplantations (e.g., heart, kidney), one might assume that waiting for a liver transplant carries an increased level of emotional, psychological and spiritual distress. Drawing on research within cancer and other organ transplantation may provide valuable insight into how and in what way this phenomenon is experienced. It is my assumption that patients awaiting liver transplantation, along with their families experience a change of quality of life and are at increased risk for psychosocial and moral distress. Furthermore, how and in what way experiencing waiting within the sociocultural context of their illness has yet to be fully explored.

## **2.1 Waiting**

Waiting is a common day-to-day experience of living that is experienced in both ordinary and extraordinary circumstances (Naef & Bournes, 2009). People wait for special occasions (e.g., birthdays, Christmas), for bad news (e.g., test results), or for difficult times in their lives to pass (e.g., illness, divorce, financial hardships) (Naef & Bournes, 2009). Not surprisingly, the extant literature has focused primarily on linear or clock time within the context of waiting as this is a reflection of how the healthcare system functions. Surgical wait times, emergency room wait times, time to



treatment (e.g., cancer treatment and diagnosis) and general access to healthcare dominate the literature on waiting. The lived, more subjective experiences of wait time have been well studied in the social sciences; however have been underexplored in medicine (Klitzman, 2007). Furthermore, embodied time is rarely mentioned in the literature surrounding waiting for a transplant. It is conceivable that what happens on this waiting journey may contribute to the comorbidity of illness, thus resulting in a poorer quality of life for both the individual and their family (Brown, Sorrell, McClaren & Creswell, 2006).

The lack of attention to and understanding of how waiting is experienced further reinforces the need for more research examining how waiting is lived out by patients and families, to provide more effective person-centered care for both patients and their families.

The literature on waiting has been described as filled with an anguishing doubt and uncertainty (Bunzel, Wollenek & Grundbok, 1992), agony (Jonsén, Athlin, & Suhr, 2000), loss (Brown et al., 2006), a decreased satisfaction with health services (Bruce, Bowman & Brown, 1998), emotionally draining (Larsson, Hedelin & Athlin, 2007), frustrating (Mulcahy, Parry & Glover, 2010), panic (Mishel, 1999), vigilance (Thornburg, 2002), feelings of embarrassment and shame (Ivarsson et al., 2011), ambiguity (Bournes & Mitchell, 2002), a bargaining with oneself (Jonsen, Athlin & Suhr, 2000) an unbearable wandering (Thornburg, 2002), physiologically disturbing (Catania et al., 2011), like living with a time bomb (Suszycki, 1988) and like watching the sand in the hour glass run out (Bunzel, Wollekenk & Grundbock, 1992). Waiting has further been described as placing one at the mercy of another's schedule

(Mulcahy et al., 2010) and as “a grueling experience of unsure stillness” (Bournes & Mitchell, 2002, p. 62). It has also been referred to as a “transitional, transformative place where individuals and their families create and recreate the self as they bridge the gulf between the old world and the new” (Sabo, 2013, p. 4). These descriptions represent only a few of the many complex, raw emotions and feelings that individuals have while waiting for something in their life. One can assume that patients and their families experience many or all of these emotions while waiting for a liver to become available and a renewed chance at life.

Being on the waiting list for a transplant not only generates anxiety and depressive symptoms, it also confines an individual’s activities of daily living (Diaz-Dominguez, Perez-Bernal, San-Gregorio, Martin-Rodriguez, 2006). Examples such as the feeling of being put on hold (MacDonald, 2006), confined and restricted (Baker & McWilliam, 2003), hopeful and a light at the end of the tunnel (Moran, Scott & Darbyshire, 2011), a time of threatening personal goals, questioning others goals for them and like a lack of input and understanding, particularly from health care providers (Ivarsson, Ekmehag & Sjoberg, 2012). For patients on the liver transplant waitlist, the opportunity for a new liver arises out of the terror of their catastrophic illness as a last chance for life (Brown et al., 2006). Patients find themselves living out a paradoxical situation of renewed hope coupled with uncertainty- when, if ever, their call will come (Brown et al., 2006).

Liver transplant patients may relate to many of the emotions of waiting cited above, given the unique and complex position they find themselves in while waiting for the death of another to provide them with a new opportunity for health and life.

This wide array of feelings, emotions and experiences may provide compelling incentive to undertake psychosocial research that includes an examination of the unique and complex life experience of waiting for a liver transplant. Although less of a focus in this literature review, patients with end stage liver disease not only wait for a suitable liver to become available, they also wait for a diagnosis, a treatment plan, specialist appointments and to be placed on the transplant list. For these reasons, additional research examining the lived experience of waiting for a liver transplant is critical in order to more appropriately provide supports and resources for patients and their families.

## **2.2 Waiting For A Liver Transplant**

Bjork & Naden (2008) of Norway conducted a 21 patient qualitative explorative design study that interviewed patients in hospital with end-stage liver disease who were placed on the liver transplant wait list prior to returning home. The purpose of their research was to explore patient's experiences of being accepted as future liver transplant recipients and their experiences of waiting following placement on the waiting list. Bjork & Naden found that nearly all of the patients described having psychological reactions during their diagnostic period, with a major theme being fear of dying before reaching transplantation. Other main themes included the patient's reduction in physical strength, an increase in mental strength and existential worrying about the meaning of life. Participants described this increase in mental strength to be influenced by their ability to remain updated on their condition by their health care providers.

The authors further described how many of these patients found their worlds changed - the taken-for-granted everyday activities that defined who they were no longer obtainable. A strength of this article is the robust nature of the findings and its value in adding to the limited understanding of the psychological aspects of end stage liver disease for those awaiting liver transplantation. Although this study only had a small number of females (sample size of 4), this should not be considered a limitation, as more males are affected with certain liver diseases, such as hepatocellular carcinoma (Yeh & Chen, 2010) and alcohol cirrhosis, as on average, men are more likely to drink excessively than women (CDC, 2013). One must also consider the context within which patients are placed on the list in Norway, in comparison to other countries. Norwegian patients wait significantly longer to be placed on the liver transplant wait list in an effort to decrease the time to transplant (Jonsen Athlin & Suhr, 2000, Baker & McWilliam, 2003). As a result, a false impression of shorter wait times and poorer overall health status emerges when compared with other countries. This limitation poses a challenge when comparing their findings to liver transplant patients in Canada where patients are placed earlier on the wait list; it presumably speaks to cultural differences in how healthcare is delivered across various countries. Such differences in the approach to healthcare delivery may make it difficult to apply findings in this population. At the same time, it does not diminish the fact that the experience is a psychologically challenging one.

In a phenomenological study that examined the experience of 6 patients waiting for a liver transplant in a large US Midwestern medical center, Brown, Sorrell,

McClaren & Creswell (2006) found eight core themes related to waiting for a liver transplant. These themes included: transformation, doctors, teams and trust, elation to despair, loss, questioning the process, searching, coping, and the paradox of time. Like Bjork & Naden (2008), Brown et al. (2006) also discovered that this period of waiting is filled with uncertainty of when, or if one would receive that fateful call for transplant. Other participants in their study related this difficult time of waiting to that of purgatory, which brings both a religious and spiritual aspect to waiting. The authors also discovered that the period was akin to “slow[ing] time down, because it’s everyday, waiting for the call” (p. 130). Waiting was also described as a time away, where a loss of ordinary and common roles diminished participation in their life outside of the wait list. The authors uncovered that patients rationalized time and uncertainty by telling themselves they have to learn to be patient with time experienced as “until transplant.. and after transplant” (Brown, et al., 2006). It is not clear if this rationalization arises out of the healthcare system’s cultural norm of a good patient as a ‘patient patient’ (Sabo, 2013).

There are numerous strengths to this research, including the use of a phenomenological methodology, which helped to uncover the meaning of the experience, and how each individual lived out his or her experience. Inclusion of implications from this research, which helps one to use and disseminate these research findings into clinical practice was also a strength. These implications for research included the need for health care providers to include family members as an integral part of the transplant team, and the need for individuals and families awaiting transplantation to network and support one another. Other implications included the

need for health care providers to acknowledge and support the notion that the time spent awaiting transplantation is individual, and must be treated this way by healthcare providers

One study examined the experience of waiting for a liver transplant for patients with familial amyloidotic polyneuropathy (FAP), a fatal hereditary disease that originates in the liver and affects the autonomic nervous system, the gastrointestinal tract, eyes, kidneys, heart and adrenal glands (Jonsen, Athlin & Suhr, 2000). Jonsen, Athlin & Suhr interviewed patients who were being assessed for placement on the liver transplantation list, and interviewed several participants a second time after their liver transplantation and one year after their initial meeting. They found two primary categories: waiting for a decision and waiting for the operation. More specifically, Jonsen, Athlin & Suhr (2000) found seven themes during this process: bargaining with oneself, powerlessness, relief and joy, impatience, agony, time to prepare and need for information and support. Although informative in the context of waiting for a liver transplant for this population, given the multi-system disease process of FAP, all of these findings may not be transferable to all individuals with end stage liver disease population awaiting liver transplant. While FAP leads to end stage liver disease with similar outcomes to other liver diseases, as mentioned above, FAP is a multi-system disease that not only affects the liver, but also can affect the autonomic nervous system, eyes, kidneys, heart, adrenal glands, gastrointestinal system and the extremities (Plante-Bordeneuve & Said, 2012). This article significantly contributes to the dearth of research on the psychological aspects of awaiting liver transplant, as patient experiences with FAP are rarely cited

in the available literature. This is a strength, as Bjork & Naden (2008) identify that different causes of liver failure produces different symptoms, therefore having an impact upon the experience of waiting.

Baker & McWilliam (2003) conducted a grounded theory study in which 12 adults waiting for a liver transplant for one year or longer were interviewed. They found the waiting period to be a process of confinement, discipline, and ultimately letting go, surrendering one's self to accept available, accessible, and appropriate resources for health. Baker & William found that participants used numerous resources to help themselves through this period of waiting, including: following instructions, seeking information and support, controlling symptoms, distraction and denial, changing attitudes, setting and achieving new goals, isolating oneself and entrusting oneself to another. This research highlights the tremendous strength of the participants, and how through sharing their thoughts, emotions and remaining confident, they are able to navigate through this trying time in their life. In comparison to other studies, Baker & McWilliam found these patients to speak more of their strengths than their weaknesses, suggesting a phenomenon, resilience may play a role in how individuals successfully adjust to waiting and challenges in their lives. Research into how and in what way resiliency may support adaptation/adjustment to waiting for a liver transplant may enhance how care is delivered to this population during this critical time.

In a large 50 patient research study examining disease coping styles of recently added patients to the liver transplant waitlist, Lopez-Navas et al. (2010) found that only 6% of patients adapted well to being on the transplant waiting list,

while 94% adapted poorly. Of these 32% had feelings of hopelessness, 50% experienced anxious preoccupation such as having an inability to make plans for the future or becoming overcome with anxiety and anger, 28% had thoughts of death (fatalism) with 30% using negation (p. 3151). Furthermore, the authors found that patients who showed maladaptive responses used a “less fighting spirit” for their coping strategy, in addition to other maladaptive behaviors such as anxiety, hopelessness and fatalism. These findings are concerning, as they highlight how few liver transplant candidates consider themselves to be adapting well to their wait for a new liver. This has potentially devastating negative health implications for their current and future health. Additional research investigating adaptive/non-adaptive processes may provide more insight into how both health care providers and families can more effectively assist these individuals with their coping and psychological health while waiting for a liver transplant.

Resilience has been defined as the ability to withstand, overcome and rebound from adversity (Walsh, 1996). Due to the arduous, challenging and life altering diagnosis of end stage liver disease requiring liver transplantation, one can postulate that an individual and their family awaiting transplantation demonstrate resiliency on a daily basis. Individuals and their families are faced with the difficult reality of this devastating diagnosis, while managing their life, health and treatment during the wait for a suitable liver to become available. As a pioneer in this field, Walsh (1996) describes resiliency in families as involving “multiple, recursive processes over time, from a family’s approach to a threatened or impending crisis situation through adapting in the immediate and long-term aftermath” (p. 268). These individuals



demonstrate significant resilience as they cope and navigate through their illness with the constant threat of declining health and even death, as they have no control over when, or if a liver transplant will become available.

In relation to the family, Rolland (1994) identified that the psychosocial demands on the family change over time with the course of a serious illness, in interaction with the family's adaptation process and life cycle. These changes in psychosocial demands and adaptation provide impetus for individuals and families awaiting liver transplantation to receive continuous psychological assessment and follow-up, as these experiences do not remain static over the course of the illness. These individuals and their families may demonstrate resiliency, as they manage to live through this intense threat to both the life and health of the individual, and the threat to the family-unit as a whole. Although many factors can help develop family resiliency, there are also many that can impede upon the ability of a family to remain resilient. Those factors that can impede family resiliency include feelings of helplessness, failure, blame, shame, guilt & despair (Walsh, 1996). Clusters of stressors with competing demands and myriads of emotions that complicate family adaptation can also impede family resiliency (Walsh, 1983).

An overarching limitation in much of the literature on waiting for a transplant is the lack of assigned definition of what it means to "wait". The lack of definition leaves the reader to ponder exactly what the authors were, in fact, measuring. This could be addressed through providing a clear definition of what the authors were using as a definition or, in some cases, by asking the participants how they would define wait and/or what wait means to them. Further research that distinctly defines

this phenomena and what it means for the participants and families included is needed to not only understand how these patients experience this time, but to have a stronger understanding of this phenomenon a whole.

Patients awaiting liver transplantation may be at an increased risk for ineffective coping during this arduous wait for numerous reasons. There are over 100 different forms of liver disease, many which can lead to end stage liver failure requiring liver transplantation for survival. The symptoms and cause of end stage liver disease can vary considerably depending on the specific disease process of the individual. Psychiatric disorders including cognitive impairment from hepatic encephalopathy, depression and drug and alcohol abuse are prevalent in this population, which places this population at an increased risk for a reduction in quality of life and potentially, coping mechanisms. In addition to the disease process and psychiatric disorders that can impede effective coping, the ability to effectively cope could be influenced by numerous factors. Hospitalization itself can impede effective coping, as it has been identified to negatively influence quality of life (Dominguez, Martin & Perez, 2010). The coping strategies and abilities of family members has also been identified as being an influencing factor of the coping ability of the individual themselves (Dominguez-Cabello, Martin-Rodriguez, Perez-San-Gregorio, Fernandez-Jimenez, Sousa-Martin & Bernardos-Rodriguez, 2012). This highlights the need for the family to be included in the psychological care provided for individuals awaiting transplantation. Anxiety and depression have also been identified to impact upon coping abilities for those awaiting liver transplantation (O'Carroll, Couston, Cossar, Masterton & Hayes, 2003, Telles- Correia, Barbosa & Monteiro, 2009). This

further underscores the need for comprehensive psychological and mental health assessments and services to be offered for individuals listed for liver transplant. As there is an impact upon both the physical and psychological health on the individual and family members awaiting transplantation, the earning potential and ability to work outside the home may be negatively impacted upon, which one could assume could negatively impede coping factors by adding an increased financial burden and a lower level of self-esteem.

### **2.3 Quality Of Life**

Studies have examined patients' quality of life and experience before and after liver transplantation, finding that individuals undergo periods of uncertainty, control, social support and spirituality (Johnson & Hathaway, 1996). This research also found the importance of family, physiological, psychological and socio-economic aspects of life on the individual's quality of life (Bean, 2005). Many of these studies were retrospective and conducted after a patient received a transplant, revealing that these patients were highly concerned with their quality of life, health care social support and financial aspects of their life (Jones & Egan, 2000). Although these studies are helpful in examining the lived experience, the fact that these studies utilized a retrospective design could be viewed as a limitation, given that recall of the experience of an event, may not hold true to the description of an event one might have had in the present moment.

### **2.4 Psychological Distress**

Individuals with end stage liver disease may experience significant illness distress while awaiting liver transplant. Illness distress associated with end stage liver

disease and transplantation affects every aspect of an individual's life, including their psychological, social, physical and spiritual health, while impacting upon their overall quality of life (Bean & Wagner, 2006). The significant distress experienced by individuals not only affects their own life, but the life of their caregivers, spouses and family members. Psychosocial distress can be defined as "the general concept of maladaptive psychological functioning in the face of stressful life events" (Abeloff et. al, 2000, p.556). How and in what way these individuals and their families function in the face of psychological distress has implications for their overall quality of life. This gives reason for further studies examining this difficult waiting period. With added insight into this psychological distress experienced by the individual and their family members awaiting liver transplant, more appropriate and comprehensive psychological and counseling services may be offered that will better meet their multi-focal needs.

## **2.5 Moral Distress**

A review of the literature has identified a significant psychological impact on both the individual awaiting liver transplantation and their family. Moral distress was first coined by Jameton (1984) to describe the inability of nurses to do what they believed to be right, due to organizational constraints. Following this, Webster & Baylis (2000) described moral distress as stemming from not only organizational constraints, but also individual and perceived constraints, which include personal failings that prevent individuals from acting in such a way that will compromise their personal integrity. Webster & Baylis found that moral distress can lead to moral residue: "the experience of compromised integrity that involves the setting aside or

violation of deeply held beliefs, values and principles” (2000, p. 223). Although research on moral distress has focused on nurses, physicians and other health care providers, one might assume that individuals awaiting the death of another in order to benefit themselves may also experience significant moral distress. Recognizing this moral distress and thus addressing it could potentially have a significant impact upon individuals and their families awaiting transplantation.

One reason for moral distress may be that someone must die in order for another to live (Youngner, 2003). This leaves patients and their families awaiting liver transplant grappling with the challenging reality that another family must experience tragedy, leaving recipients and their families distraught, as they spend their time waiting for the death of another (Zink & Wertlieb, 2004). Others awaiting transplantation have described this as “just sitting waiting for someone to die” (Robertson, 2005, p. 172). Brown et al. (2006) found that even through the participants’ anticipation and desire for a transplant, individuals awaiting transplant realize this desire comes at the cost of another’s life. Sminoff & Chillag (1999) discovered that some in-patients listened to the sound of the helicopters landing with the hopes that these might carry “their” organ, but became distressed when they realized that this meant the death of another. These mixed feelings can undoubtedly give rise to ‘survivor guilt’ on the part of the patient (Sminoff & Chillag, 1999, Sanner, 2003). Such feelings may be more significant in transplant patients whose organ can only come from a cadaver organ, such as a heart or liver. These emotions may be perpetuated long after the transplant has occurred, giving rise to the ‘survival guilt’ phenomenon described in the literature.

In a study examining heart and kidney transplant recipients after transplant, Sanner (2003) found that many recipients could not avoid wishing that a suitable donor would die, with many donors questioning if they themselves caused the donor to die. The recipients in Sanner's (2003) study also found it extremely unfair that others had to die for another to live. These findings provide added reason for more research to be done to better understand these emotions, so that health care providers can help individuals with these psychologically challenging feelings. Other research found that patients related having to function with a certain degree of denial, as it is through this denial they were able to live each day (Brown et al., 2006, Sanner, 2003). Furthermore, these findings could help healthcare providers in understanding the moral and ethical dilemmas that some of these individuals and their families experience.

It is conceivable that if moral distress experienced by those awaiting transplantation is correctly identified and addressed, patients and their families may be less likely to experience moral residue following periods of unresolved moral distress. Furthermore, with the right psychosocial supports patients and their families may have the ability to live out this time in acceptance rather than denial.

## **2.6 Mental Rollercoaster**

Throughout the liver transplant wait list literature, there has been a focus on the mental rollercoaster or necessary psychological and mental coping in order to get through the waiting process. Brown et al. 2006 found that many participants asked how they could possibly function knowing the burden of liver transplant was hanging over their head. The authors suggested that patience is a quintessential skill one must

master while waiting for a liver transplant. Jonsen, Athlin & Suhr (2000) found that patients waiting for a liver transplant transitioned from powerlessness to relief and from joy to agony, which further highlighted the mental rollercoaster individuals may find themselves on while waiting for a transplant. Similar to this, Forsberg, Backman & Moller (2000) found that in addition to uncertainty, patients awaiting liver transplant experienced an array of feelings including those of anticipation, joy and acceptance. This constant mental rollercoaster emphasizes the need to acknowledge, validate and in turn normalize the myriad of feelings and emotions.

## **2.7 Uncertainty**

Uncertainty is defined as the inability to establish the meaning of illness-related events (Mishel, 1988). The studies within the liver transplant literature found the period of waiting for a liver transplant to be filled with a high level of uncertainty and fear questioning what the future would bring (Brown et al., 2006, Bjork & Naden, 2008, Johnson & Hathaway, 1996, Bean, 2005, Lumby, 1997, Forsberg, Backman & Moller, 2000, Wainwright, 1997). Mishel (1988) identified that managing the uncertainty associated with an illness may be a vital task in adaptation. High levels of uncertainty have been linked to increased emotional distress, depression and anxiety within many chronic and life threatening illnesses (McCormick, 2002, Mishel, 1999, Bailey, Wallace & Mishel, 2007). Furthermore, uncertainty frequently arises from a fear of dying before the transplant or developing another life-threatening illness such as cancer while waiting (Bjork & Naden, 2008).

Studies have also highlighted how patients may question whether or not they are really ill (Johnson & Hathaway, 1996, Wainwright, 1997). Although the study by

Johnson & Hathaway had similar findings to other studies reviewed, only one participant was included in the study. This is indicative of a case study, which provides both strengths and weaknesses. It is a strength, as it contributes to the liver transplant research by giving an in-depth view of one individual's experience, but also a weakness, as case studies and small sample sizes limit transferability to other individuals experiencing this same phenomenon. However, the fact that these themes are harmonious with those of other similar studies helps to validate study findings. These findings would suggest a need for further studies that examine whether questioning the presence of illness is a form of coping for an individual awaiting transplantation. Studies that utilize a larger sample size, a clearly articulated definition of waiting and mixed methodology may provide a more robust picture of this experience.

Although the experience of waiting for a liver transplant is unique, there are similarities between those waiting for a liver transplant and those waiting for other solid organ transplants. The experience of having end stage organ failure, being placed on a waiting list and waiting for the death of another to receive a transplant holds many similarities for individuals, particularly the myriad of emotions, ethical and existential questioning as well as uncertainty (MacDonald, 2006, Moran, Scott & Darbyshire, 2011, Haugh & Salyer, 2007, Pelletier, 2008).

Similar to those with end stage liver disease waiting for a liver transplant, renal transplant is considered the gold standard for most individuals diagnosed with chronic kidney disease (Murphy, Trevitt, Chamney & McCann, 2011). However, unlike patients with end stage liver disease, patients with end stage renal disease have



several modalities for treatment, including peritoneal and hemodialysis (Moran, Scott & Darbyshire, 2011). Research on the experience of waiting for a kidney transplant has found that that patients live in hope and uncertainty while their lives are on hold (Moran, Scott & Darbyshire, 2011). Additionally, research has shown that patients and their families experience a change in their way of life, avoid disappointment, change, uncertainty (Pelletier, 2008) and are significantly more depressed and anxious while waiting for their transplant (Corruble et al., 2010). Research has also shown a significant decrease in these emotions following the transplant (Corruble et al., 2010), highlighting the impact waiting has on both patient and family members.

Similar to patients with end stage liver disease, patients on the waitlist for a heart or lung transplant often experience a gradual deterioration during their wait for a transplant, with many facing an expected survival of less than one year (Ivarsson, Ekmeahag & Sjoberg, 2012). Research on the wait for a heart or lung transplant has shown that these patients achieve confidence and trust by receiving information and support, which, while helpful, may be insufficient to counter the negative emotions arising from a lack of understanding of treatment options and the struggle with their life-threatening illness and insecure future (Ivarsson, Ekmeahag & Sjoberg, 2012). A comparable study, exploring patient and family members perceptions of time spent waiting for heart transplantation, Hugh and Salyer (2007) found the most common theme was tolerating uncertainty specifically when, or if they would receive a donor heart (Haugh & Salyer, 2007).

In a study examining the lived experience of waiting for a lung transplant, Naef & Bournes (2009) noted how patients found this period immensely difficult and

agonizing, filled with expectation of the end prize, finding strength in others and engaging in activities. Similar to this, MacDonald (2006) used an exploratory approach to examine how patients with cystic fibrosis and their caregivers coped with waiting for a lung transplant. MacDonald interviewed patients prior to and after transplantation. Patients felt displaced, disordered, their lives in limbo necessitating a significant readjustment to wellness. As with many of the studies, the retrospective nature of this study raises the question of recall bias, which may lessen or heighten perceptions of the waiting experience.

Due to the complexity and trajectory of the diagnosis, waiting is an unavoidable experience for cancer patients and their families (Sabo, 2013). Similar to patients listed on the liver transplant waitlist, cancer patients also experience numerous waiting periods during the course of their diagnosis and treatment. More specifically, many women with breast cancer have to wait for a definitive diagnosis, family physician appointments, a specialist referral, treatment, and follow-up treatment and to find out whether treatment was successful (Rajacich, 2007). Research on female breast cancer patients has shown that over half of these patients are quite or very anxious during the pre-diagnostic phase of their illness (Pineault, 2007, Brocken, Prins, Dekhuijzen & van der Heijden, 2012). One phenomenological research study used feminist inquiry to gain an understanding of the meaning of waiting for women with breast cancer, and found that women with breast cancer relate this experience as being like waiting on a rollercoaster, a period of uncertainty, a process and a time where they are trying to remain normal (Rajacich, 2007). Lebel et al. (2003) conducted a study with women waiting for a breast biopsy, and

discovered that to help decrease stress and anxiety levels that women waiting would prefer to be more accurately informed of the exact date when they would have their biopsy. When transferring these findings to populations awaiting liver transplant, this research further outlines the challenges transplant patients and their families face, as the uncertainty of their transplant date is much greater.

It would appear that uncertainty is a shared experience for many patients regardless of the type of end-stage organ failure. How and in what way uncertainty is experienced and what resources and supports are needed for the individual needs to be further explored, particularly as it pertains to liver transplantation in light of the paucity of research in this population. Rather than taking a retrospective approach, studies should explore the experience of waiting as it is currently unfolding to provide a more reflective depiction of how waiting is lived out.

## **2.8 Sociocultural Context Of Illness**

Individuals with end stage liver disease and their families experience this debilitating and chronic illness within the larger context of their place in life and society. Similar to other chronic illnesses, individuals with end stage liver disease have frequent contact with family and friends, as well as the health care system. These interactions, if negative or unsupportive, can lead to a diminished quality of life (psychological, physical and mental health) further reinforcing a need to consider the sociocultural context within which the illness is experienced. Due to the constant interaction one has with their outside world, one can assume that the cultural context in which these individuals experience waiting for a liver transplant can have a significant impact upon how and in what they experience this psychologically

arduous time. Illness is highly influenced by culture, as it is considered to play an intimate role in our systems of meaning and rules for behavior, as our culture shapes how we experience, cope and perceive with illness and disease (Kleinman, 2006, Kleinman, 1975). Culture plays an important role in the presentation of illness and cultural differences can impact upon the treatment options an individual may consider (Bhugra & Becker, 2005).

One could also assume that culture can impact upon an individual's outward expression of their experience of waiting, as certain cultures do not embrace more outward displays of emotion and embrace a stoic expression, while others embrace this emotional expression. Not only have there been no Canadian studies that have examined the lived experience of waiting for a liver transplant, few studies have examined this experience from a cultural perspective, which highlights the need for more research to be undertaken to better understand and articulate how the cultural context in which one experiences their illness impacts upon this experience.

Given that Canada is a mosaic of many cultures, there may be significant variation in how individuals experience their illness through a cultural lens, given the potential for differences in religion, social expectations, religion, class, ethnicity, marital status (single, common law, married, same sex marriage or partner) and gender. Considering these cultural differences is essential in gaining an understanding of how these individuals experience their illness and time spent waiting for a liver transplant, as these may help us in gaining a better understanding of how these individuals live out and assign meaning to their illness experience.

## **2.9 Stigma**

Stigma is conceptualized as a powerfully negative way of acting towards another that underlies the beliefs and practices of others (Butt, Paterson & McGuinness, 2008). It has been described as a complex, individually experienced phenomenon in which individuals experience and express both overtly and subtly (Fife & Wright, 2000). Stigma has been identified to increase stress associated with illness, thereby affecting physical, psychological health and quality of life (Fife & Wright, 2000). Furthermore, it has been established that stigma has a profound impact upon spouses, caregivers and family members of those who experience it, which can further impact upon the psychological distress the individual with the illness experiences from it (Demi et al., 1997). Rarely cited within the literature on solid organ transplants, few studies have examined the experience of stigma as it relates to patients with liver disease, and how this affects patients' psychological and mental health, as they cope with their illness (Sogolow, Lasker, Sharim, Weinrieb & Sass, 2010, Fahey, 1999, Wainwright, 1997).

Patients awaiting liver transplant may require additional psychological services, counseling and assessment than patients awaiting other solid organ transplants, particularly if their disease resulted from alcohol or drug misuse; the associated self-blame may make it difficult for these individuals to move forward with their lives, accept subsequent outcomes or face death (Brown et al., 2006). Similar to this, Siminoff & Chillag (1999) found that patients whose illness was due to alcoholic cirrhosis worried about donor families being disappointed, if they found out where their loved ones liver had gone. This self-blame, worry and guilt can negatively impact an individual's psychological, mental and physical health,

including the health of their potential future transplant. Understanding this aspect of the disease and ways to better support the psychosocial health and well-being of liver transplant patients should become a priority given the potential cost to the healthcare system if these issues continue to be ignored.

Research into patients with hepatitis C has uncovered that the stigma and discrimination experienced by patients with hepatitis C is just as poisonous and threatening as the disease itself (Richmond, Dunning & Desmond, 2004). This is a concern, as this harmful stigma stems from the harsh and often-untrue societal assumption that individuals with liver disease are alcoholics or drug users. Patients diagnosed with either hepatitis B or hepatitis C experience stigma; the former is a sexually transmitted infection while the latter is most frequently associated with injection drug use (Drazic & Caltabiano, 2013). The suffering and discrimination experienced by individuals diagnosed with Hepatitis C leading to chronic liver disease has been likened to that experienced by individuals with HIV (Ingram & Hutchinshon, 1999). This is significant, as hepatitis C has been identified as the leading cause for liver transplantation in the developed world (Golden, Conroy, O'Dwyer, Golden & Hardouin, 2006). Although not all patients with end stage liver disease have hepatitis C, the stigma faced by patients with all forms of liver disease highlights a need for a greater understanding of the negative effect this disease has on both patient and family, as well as a need for public education to counter stigma and misunderstanding. Wainwright's 1997 grounded theory study found that patients awaiting liver transplant assigned meaning to the illness experience complicated and challenging when overall attitudes of families, friends and society, believed they had

“drank themselves” into their condition (Askari, 2007).

In their study examining stigma experienced by woman with primary biliary cirrhosis (PBC), Sogolow et al. (2010) found that higher levels of reported stigma were associated with diminished mental and social aspects of their quality of life, as well as a greater uncertainty in their illness trajectory. The authors also noted that depression, fatigue and younger age were key predictors of stigma. This study is considered to be pivotal work on stigma and liver disease, as it was the first gender-based study to explore stigma as an experience of primary biliary cirrhosis. Zickmund et al. (2003) found that women with liver disease identify experiencing higher levels of stigma than men. To date the research appears to be mixed with some studies suggesting little to no difference in the experience of stigma across gender (Golden, Conroy, Dwyer, Golden & Hardouin, 2006). Further research examining both male and female patients perceptions of end stage liver disease will help to identify the similarities and differences experienced by these individuals. In turn, this may be instrumental in tailoring individual patient and family-centered health care services to the needs of these individuals and their families.

### **2.10 Healthcare Providers’ Attitudes And Beliefs**

While the majority of research examining patients perceived stigma from health care providers focuses on individuals with HIV/ AIDS or mental illness, a few studies have examined stigma from healthcare providers (HCP) within the context of chronic liver disease. Research on patients diagnosed with hepatitis C found that patients felt the highest levels of stigma from family followed by healthcare providers (Moore, Hawley & Bradley, 2008). This is a disturbing finding when one considers

the frequent contact patients have with the healthcare system and their family members. Research into patients with other chronic liver diseases has found that health care institutions are common places to experience stigma (Zickmund, Ho, Masuda, Ippolito & LaBrecque, 2003, Butt, Paterson & McGuinness, 2008, McCreddie, Lyons, Horsburgh, Miller & Frew, 2011, Crockett & Gifford, 2004, Stewart, Mikoca-Walus, Harley & Andrews, 2012 & Sogolow et al., 2010). These findings are alarming, highlighting the need for more research to enhance HCPs understanding of how and in what way patients with chronic liver disease and their families perceive and cope with this prevailing stigma, particularly that at the hands of their health care providers. Furthermore, this study may help HCPs to better understand the role their personal values and beliefs may play in how liver patients and their families perceive and cope with their illness as they wait for the transplant.

### **2.11 The Experience Of Waiting Among Spouses And Family Members**

Individuals do not experience their liver disease or wait for a liver transplant in isolation. Research examining family members of individuals waiting for a transplant has identified that family members want to be recognized as an important partner in the transplant experience (McCurry & Thomas, 2002). Better understanding the experiences of family members of those awaiting organ transplant is essential. Spouses and family members are often the primary caregivers for their chronically ill family member at home, both pre and post-transplant. Not only is the care family members provide critical to the physical and psychological health of the individual awaiting transplant, many transplant centers will not place individuals on the transplant list without sufficient family or caregiver support. The requirement for



family and caregiver support has been put in place by many transplant centres, as it is considered crucial to the recovery of the organ transplant recipient. The role of caregiving can fall upon any family member or friend; however the role frequently falls upon the spouse, as this is most often the closest person to the chronically ill person.

A small number of studies have exclusively examined the family's experience of waiting for a liver transplant. Findings suggest that many families felt their life was controlled by the transplantation and a return to normal family life such as it was before the transplant impossible (Mendes & Bousso, 2009, Chou, Chen, Chen, Chen & Mu, 2008). This lack of control and negative emotion underscores the need to better understand the families lived experience of waiting for a liver transplant, given the integral role the family has in both the life of the individual, and the experience as a whole.

Other literature has examined spouses' experience of waiting for a significant other to receive a transplant. Casida, 2005, Williams, 1991, Collins, White-Williams & Jalowiec, 1996 conducted research into how spouses manage life and waiting as their significant other awaits heart transplantation. Casida (2005) found that spouses go through numerous stages while their spouse awaits a new heart; feelings of guilt, realization of the severity of illness, fear and anxiety, and the caregiving role itself places an overwhelming burden on caregivers challenging their ability to live with hope. Spouses reported an expectation that they would take on the role of caregiver; this is particularly prevalent for women where societal expectations of women as natural caregivers and nurturers places them in an unenviable positions should they

oppose the notion. Unlike other end-stage organ diseases, the lack of life sustaining devices, medication or treatment for patients with end stage liver disease further complicates the experience of waiting.

Similar to Casida (2005), Collins, White-Williams & Jalowiec (1996) found that the spouse of an individual awaiting a heart transplant focused primarily on maintaining the life of their spouse. Energy was directed at the ill spouse with little thought given to their own personal needs. They also felt a need to remain as close as possible to the ill spouse. Williams (1991) found that spouses live their life on hold. This refers to the cognitive and behavioral responses that occur in the spouse during the waiting period for an organ transplant. Williams (1991) related that during this “life on hold” the spouse focuses all thoughts, actions and energy on the life of their spouse, the transplant candidate. Williams (1991) found that many spouses live in limbo, and do not plan any future events, as all efforts are focused on maintaining donor health while waiting for a transplant. This may be due, in part, to a lack of control over when, or if their loved one will receive a transplant.

Consistent with these findings, Collins et al. (1996) also found that the greatest fear of the spouse was that the patient would die before a suitable donor could be found. Fear affected their ability to eat right, exercise, sleep, and engage in routine day-to-day activities in an effort to conserve their own energy. A strength of this study is its cross-sectional design, as the authors were able to identify that among their sample, spouses of individuals waiting more than 6 months reported higher levels of self-stressors than those whose spouse had been waiting less than 6 months.

Further research examining how spouses cope with waiting for a transplant may help health care providers and policy makers to better tailor psychological health services and assessments for donors and their families. This is critically important for the psychological health and well-being of transplant candidates, as other research has found that the behavioral disengagement of spouses is directly associated with depression in the candidate themselves (Burker et al., 2006). This highlights the need for further research to be done that examines the spousal experience of caregiving and caring for a spouse waiting for an organ transplant. Without this knowledge, effective programs and services are unlikely to be created nor offered for these patients and their families.

Other studies have examined spousal experiences among patients undergoing lung transplant, where there are limited treatment options to help bridge the patient to transplant. Kurz (2002) examined spouses of lung transplant candidates and recipients, finding that spouses who were caring for lung transplant candidates during the waiting process, had higher levels of caregiver strain than those who were caring for a spouse post-transplant. More research is needed to understand the impact on quality of life among caregivers in the period preceding a transplant as the majority of the research literature focuses on experiences of the transplant itself or life post-transplant.

Gray, Fitch, Phillips, Labrecque & Klotz (1999) studied newly diagnosed men with prostate cancer and their spouses and examined their journey between diagnosis and surgery. The authors found that the news of diagnosis came as a shock for both partners which lessened over time, a readdressing the marital relationship which often

lead to a sense of renewed connection, a need for couples to decide who to inform about the diagnosis, a seeking of normality in the couples lives and attempts to minimize the impact and the anxiety of the upcoming surgery by one or both partners. Although this study examined the wait for individuals and their spouses with prostate cancer, the experience of shock, anxiety, wait for surgery and seeking of normalcy, may be similar to experiences of some individuals and their spouses awaiting transplant.

A 2013 exploratory study by Sabo, McLeod & Couban used a mixed-method design to uncover the effect of caregiving on the health, burden, depression and well being of spouses of individuals undergoing hematopoietic stem cell transplantation. The authors found four core themes; the need for reassurance and hope, uncertainty, waiting and altered relationships. The authors studied these individuals across time, finding that waiting and uncertainty held the greatest meaning for spouses across all periods of time. A strength of this study is the use of a mixed-method design, which allows both qualitative and quantitative data to better understand the complex experience of waiting for these spousal caregivers. These findings highlight the need for further studies to be done that examine the caregiving experience for other spousal caregivers, such as those caring for spouses awaiting liver transplantation.

## **2.12 In Summary**

The research on liver transplantation remains primarily quantitative, focusing on aspects of organ availability, graft survival rates, post-transplant experiences and quality of life for individuals undergoing organ transplant. Although valuable, this research leaves out the individual's experience while waiting for a suitable organ to

become available. This review identified an overall need for further research to be done to examine what and how the experience of waiting for an organ transplant is lived out. More specifically, further research examining how individuals and their families live out the waiting period of waiting for a liver transplant is needed. It is anticipated that the results of this study will enhance health care providers understanding of the experience and better position them to provide more focused, person-centered care to meet the unique needs of both the patient and their families. To that end, the research methodology and study design described in Chapter 3, are informed by the need for an approach that took into account the context and subjective nature of waiting for a liver transplant.

### **Chapter 3 Paradigm, Methodology & Analysis**

This research study sought to uncover and explore the experience of individuals and families awaiting liver transplantation. Based on the study purpose, a qualitative paradigm was used. Qualitative research methods are particularly advantageous when there is little known on a topic and the phenomenon in question is not quantifiable (Morse, 1991). Qualitative researchers study people and things in their natural setting, and seek to interpret phenomena in terms of the meanings people give to them (Denzin & Lincoln, 1994). Using a qualitative paradigm for exploring the individual and family lived experience of waiting for a liver transplant was well-suited, as it has received little attention to date within the extant literature. The use of a qualitative paradigm allowed me to explore how these families live out this experience, and the meaning they assign to this experience. It helped me uncover the experiences that these individuals and families have, while uncovering the meaning and search for commonalities and differences among these unique experiences.

#### **3.1 Research Paradigm: Interpretive Phenomenology**

To understand the lived experience of waiting for a liver transplant for the individual and caregiver, a qualitative paradigm was used. A paradigm is a “systematic set of beliefs, together with their accompanying methods” (Lincoln & Guba, 1985, p. 15). Furthermore, given the search for meaning and essence of a particular experience, a phenomenological methodology was used, as it appeared to be a natural fit given the guiding research questions and purpose. Phenomenology is frequently used as a method of nursing inquiry as it aligns with the art, philosophy and science of nursing (Lopez & Willis, 2004). Phenomenology seeks to gain a

stronger grasp of what it means for an individual to be in the world, taking into account the sociocultural traditions that give meanings to our ways and our life (Van Manen, 1990).

Phenomenology differs from all other sciences such as psychology, biology or physics, as it seeks to gain insightful descriptions of how we pre-reflectively experience the world, without classifying or abstracting it (Van Manen, 1990). Unlike experimental and quasi-experimental approaches, phenomenology is less concerned with the quantifiable aspects (e.g., how often, when) of an experience; rather, it places emphasis on gaining an understanding of the nature or essence of the lived experience (Van Manen, 1990). Although phenomenology can be viewed as both a research method and philosophy (Dowling, 2007), it was utilized as a methodology to explore the lived experiences of individuals and family members awaiting liver transplantation. Interpretive phenomenology philosophically and methodologically underpinned my study design; philosophically it framed my study within the context of understanding the lived experience of these families, and methodologically it provided the backbone, structure and research methods of how I uncovered and interpreted this phenomenon of waiting.

Phenomenology has numerous branches, but is generally understood as a way to explore human experience. In phenomenological research, the word methodology usually refers to the philosophical framework, assumptions and characteristics of the human science perspective (Van Manen, 1990). The two most frequently used branches of phenomenology include descriptive, which aims to describe a phenomena's general characteristics to determine the meaning of an experience

(Giorgi, 2008) and interpretive or hermeneutic, which goes beyond the description to look for meanings embedded in life experiences and practices (Lopez & Willis, 2004).

Following World War I, Edmund Husserl (1859-1938), a German Mathematician and Philosopher, sought to create a new philosophical approach that would give certainty to a seemingly crumbling civilization. This scientific approach, descriptive phenomenology, focused on consciousness and how individuals understand and clarify the sense of the world they live in (Husserl, 1962). Husserl described descriptive phenomenology as “the methodology through which I come to understand my ego and life of consciousness in which and through myself the entire objective world exists for me, and is precisely as it is” (Husserl, 1975, p. 8). Husserl proposed that people can be certain about how things present themselves to their consciousness, and rejected the belief that objects in the external world exist independently of one another (Groenewald, 2004).

Husserl believed that researchers must bracket themselves to provide phenomenological reductionism, a stance in which the researcher suspends their own beliefs in the reality of the natural world in order to study the essential structures of the world without bias. Husserl did not believe that the influence of life experiences of the interpreter belonged in the description of the experience under study. He posited that the goal of bracketing for the researcher was to achieve transcendental subjectivity; simply, the impact of the researcher is continually assessed, in order to neutralize biases and preconceptions, in order that the researcher would not influence the individual being studied (Lopez & Willis, 2004).



Martin Heidegger, a student of Husserl modified and built upon the work of his teacher. He challenged some of Husserl's assumptions surrounding how phenomenological inquiry should be conducted. Heidegger believed that phenomenological inquiry should move past description towards a higher level of understanding through interpretation, sometimes referred to as hermeneutics. Heidegger introduced the concept of the meaning of *dasein*, that of "being in the world". Heidegger asserted that one of the most fundamental aspects of life is spatiality, meaning that things are remote or close. Heidegger rejected Husserl's notion of bracketing and phenomenological reduction. Instead, he proposed that understanding does not occur without presuppositions (McConnell-Henry, Chapman & Francis, 2009). Understanding cannot occur without the researcher's lived experience, therefore the researcher must carefully reflect on their position in the research and how this impacts upon the research. Heidegger (1962) proposed a threefold fore-structure for researchers to use; fore-having, fore-sight and a fore-conception. That is, we come to all situations with a familiarity (past experience of fore-having), that we have a point of view (current or fore-sight) from which we will make an interpretation (assign meaning or fore-conception). As individuals, each of us have expectations, prior experience, knowledge, understanding values and beliefs informing how and in what way interpretations of phenomena are made. Therefore, as researchers we cannot attempt to bracket ourselves from what it is we are seeking to interpret.

One of Heidegger's fundamental concepts was that of the hermeneutic circle. First introduced by Schleiermacher, the hermeneutic circle reinforced the reciprocal

activity between pre-understanding and understanding (Moran, 2000). Within the hermeneutic circle, Heidegger suggested that the interpreter begins by first examining their own interpretations of the phenomenon of interest then move from the whole to the parts of that being examined (Earle, 2010). This Heideggerian philosophy views the interpreter as playing a pivotal role in the 'being in the world' of the participant. In uncovering the meaning of a subject, the universal structures of being as they manifest themselves in the phenomenon of interest become uncovered or illuminated (Heidegger, 1962). Meaning can then be uncovered to gain an enhanced understanding of the meaning individuals give to a phenomenon they are experiencing such as that of awaiting a liver transplantation

The use of the interpretive paradigm in this study helped to emphasize and understand meaning individuals give to their actions and thoughts. The world of transplantation research has been highly medicalized, which while important, lacks the understanding of the lived, embodied experience of the individual and their family. As Benner (1994) relates, caring practices and healing relationships are often marginalized in the face of medicalized treatments and procedures. In leaving this experience largely unaccounted for, interpretive phenomenology becomes an attractive alternative research choice for understanding the phenomena of waiting for a liver transplant. Such an understanding may be helpful in improving care delivery within the liver transplantation population.

## **3.2 Theoretical Framework**

### **3.2.1 Family Resiliency Theory**

Resiliency can be defined as the capacity to rebound from adversity strengthened and more resourceful (Walsh, 2006). Family resilience refers to “coping and adaptation processes in the family as a functional unit” (Walsh, 2006, p. 15). Walsh proposed utilizing a systems approach to understand how family processes negotiate stressors and how these processes can enable families to overcome crisis and prolonged adversity. Taking a systematic view presupposes that family strengths are drawn on to overcome adversity. This systematic approach looks beyond the individual experience of family members to consider broader influences (i.e., relationships, siblings, spouses extended family and friends) and how these impact upon the family context such as the ecological perspective, social and developmental context and a family-life cycle approach. Such an approach does not prescribe one model as a more effective fit with all families; rather, aspects of her framework could be applied to any family experiencing crisis or adversity.

In understanding family resiliency through the use of her framework, Walsh (2006) asserts that any crises or adversity among one individual, has an impact and rippling effect on the entire family unit and its functioning. In the family resiliency framework described by Walsh (2003), key family processes occur during these crises that helps the family to rally together in attempts to effectively reduce stress, dysfunction and alleviate burden. Walsh’s framework provides a multi-systematic assessment that is most advantageous when working toward understanding family resiliency. This multi-systematic approach acknowledges the ecological and developmental perspectives that impact upon the inner workings of the family unit.

From an ecological perspective, problems and crises within the family are seen as the result of the interaction between individual members of a family during stressful life experiences and social contexts, particularly those that render the individual vulnerable (Walsh, 2003). Although all have families have daily interactions with stressful life experiences, it is those interactions that occur during times of significant stress and difficult social contexts that can potentially render the family vulnerable, thus creating problems. These family problems are seen as being produced by stressful experiences during a time of family vulnerability, such as during a family members' illness or diagnosis. Walsh shares that biological symptoms such as illness, death or other variables such as the families' socioeconomic status can influence the families' vulnerability and the perception of these problems as a result of the family's interactions. Significant psychological, emotional and mental distress may be produced when the vulnerable family unit is unable to cope with these problems effectively as an entire family unit (Walsh, 2003). From a developmental perspective, Walsh describes how the developmental life cycle and where the family members are, as a whole, within the life cycle can impact upon and create family stressors that effect the family dynamic and unit as a whole.

The framework identifies that family resiliency encompasses differing adaptation processes over time that change with the stage and position of the family within the crises or stressor. Walsh also identifies that a family who is able to effectively cope with one stressor, may be initially unable to cope in the face of multiple external and internal stressors. When viewing a family in which one individual is awaiting a liver transplant, Walsh's framework may help us to

understand that although the family may be able to cope with the initial diagnosis of liver disease, the added burden of the long wait for a liver transplant may render the family unable to effectively cope. The ability of the family to cope with the arduous time of end stage liver disease and the uncertainty of the arduous wait for a liver transplant may impact upon their ability to remain resilient in the face of this adversity.

Factors that can support family resilience include mutual support, teamwork in facing life challenges, spirituality, identifying family strengths, flexibility, continuity and shared leadership (Walsh, 1996). One can assume that supports for the family awaiting liver transplantation as a unit could increase the capacity for this resiliency to occur, leading to an increased quality of life through an increase in psychological, mental and emotional health. These supports may help families to develop adaptation skills and ultimately develop the ability to remain resilient in the face of their family illness crisis. With these supports, families may be available to view this time in their life in a positive light, and potentially experience growth as a family unit. Identifying family strengths, resources and capabilities can help families to remain resilient through future challenges they face as a family unit.

Using Walsh's framework for family resiliency can assist practitioners that work with families in helping to guide interventions and processes that lead the family to identifying their strengths, resources and abilities to overcome the issues or problems causing adversity and crisis. This strengths-based approach framework can help families to make meaning of their difficult situation and provide potential

options for managing the situation, which in turn strengthens families abilities for problem-solving and future resiliency (Walsh, 2003).

### 3.2.2 Uncertainty In Illness Theory

The Uncertainty in Illness theory first introduced by Mishel in 1981 stated that uncertainty is a cognitive state in which the individual is unable to assign values to objects and events due to lack of sufficient cues. Mishel expanded on the work of psychologists, who first categorized uncertainty as a cognitive state that resulted from inefficient cues (i.e, information about a particular event) and applied the work of Lazarus and Folkman (1984) on models of stress and coping to apply the concept of uncertainty during illness. Mishel stated that an individuals cognitive schema; a persons subjective interpretation of illness, treatment and hospitalization, significantly impacts upon their ability to assign values to an event or object, such as illness. Mishel relates that the inability to assign value or meaning results in uncertainty, and this results in the inability to have a clear conception of a stressful situation (Mishel, 1981).

Mishel expanded upon her work in 1990 to reflect the ever-growing medicalization of illness in the Western world. Mishel identified the increasingly significant need for individuals to feel in control of their situation and the importance of having a sense of predictability in their life and illness. Mishel added components of the chaos theory to more accurately represent how individuals, particularly how those facing chronic illnesses conceptualize the imbalance and volatility that this creates in their life, and ultimately how they are able to cope with the uncertainty they are faced with to find meaning.

Mishel (1981) shared that increased uncertainty results in increased psychological mood disturbance (e.g., depression), avoidance of issues creating uncertainty and severe emotional distress (e.g. crying, mood swings). She further asserted that the longer a person experiences this uncertainty, the more likely they are to experience extreme stress. Mishel suggested that uncertainty can come from many sources, including situations with ambiguity, complexity, lack of consistent information or unpredictability. For example, when considering families facing liver disease, health care providers are in an excellent position to help with this uncertainty by promoting interpretation(s) of the events and engaging in discussion with the patient. Mishel's theory could be directly linked to patients waiting for a liver transplant, as the available literature examining their phenomena identifies that they experience extreme stress (i.e, physical, emotional and emotional) ambiguity (i.e, lack of concrete information, disconnect from health care providers and institutions) complexity (i.e, disease processes) and unpredictability with regards to when, or if they will receive their potentially life-saving liver transplant.

Health care providers can help individuals to view uncertainty as an opportunity, rather than as a threat (Mishel, 1981). This occurs when an individual has a strong understanding of a situation, and when they have the ability to successfully cope with a situation. Mishel also asserts that in prolonged periods of uncertainty, with assistance, patients can move to viewing the uncertainty within a more positive perspective. Relating this to the population awaiting liver transplantation, health care providers can work with patients and families in several ways. Health care providers must first assess individuals and families for uncertainty;

without this assessment there can be no intervention. Health care providers can help to provide clear information that aligns with the families' health literacy levels, while ensuring that the family understands the information being shared with them. They can meet frequently with the family and its members individually, to ensure that all members' questions are answered and concerns are addressed. Those providing direct care for these families can ensure that all appropriate and available resources (i.e., social work, occupational therapy, physiotherapy, psychology and/or spiritual care) have been consulted or discussed, particularly for those living outside of urban areas where these services are traditionally more easily accessed. Ultimately, health care providers are situated in an optimal position to help individuals and families assign a cognitive schema to their experience, which will then help to provide families with the tools for effective coping strategies.

Applying this theory to the research question helps one to understand the psychological stress and challenges these patients who are waiting for a liver transplant are experiencing. These patients and their families live day to day uncertain of if, or when, they will receive a liver transplant. Without the proper information, resources and coping strategies, Mishel helps us to understand the uncertainty and associated stress these patients find themselves with; given that these patients are isolated in their own communities, without a specialized transplant health care provider. If families can make meaning of their illness and assert positive meaning, they will be in a position to enhance their quality of life while they wait for a liver to become available. Health care providers can work with families to help them find



positive meaning in their illness, which can have positive health benefits for the entire family unit.

### 3.2.3 Phenomenology, Resilience Theory And Uncertainty

Applying Walsh's framework of family resiliency to the research question of how individuals and families live out the time spent waiting for a liver transplantation helps me to understand the role that resiliency plays during this period of waiting.

This framework was used to support this research study, as it provided an understanding of how families give meaning to their experience, and how they work as a unit to cope during this arduous wait. Walsh's framework supported the research question, and is compatible with the use of a qualitative interpretive methodology, as it seeks to understand the experience of families as it is lived. Families most often experience this time of waiting as one family unit, and must learn how to manage during this time of uncertainty and illness.

Mishel's uncertainty in illness theory highlights that individuals and families come together to assign meaning to their experiences of illness. Applying the uncertainty in illness theory to individuals and families awaiting liver transplant, one might postulate the challenges families face in coming together to remain resilient in the face of the uncertainty and difficulty of waiting for a liver transplant. Mishel asserted that uncertainty can lead to significant psychological and physical health problems. The longer the person (or family) experiences this uncertainty, the greater the stress. Considering uncertainty within the context of the family resiliency framework highlights how uncertainty around transplantation has the potential to lead to major stressors (psychological, mental, financial, emotional and physical) on the

family as a larger unit. At the same time, uncertainty considered within the context of resilience has the potential to shed light on how patients and families may overcome adversity to achieve a more positive perspective of life, the illness experience and waiting.

Walsh (2003) describes that during times of significant adversity, key family processes occur that help the family to come together in attempts to effectively reduce stress, dysfunction and alleviate burden. During this time of great uncertainty as the family waits for a transplant to become available, their ability to persevere through adversity may demonstrate significant resilience. Both Mishel's uncertainty in illness theory and Walsh's family resiliency framework identify that if families are unable to rally together to assign meaning and persevere through the stressors they may experience significant psychological, mental and physical stress. To reduce these potential stressors, these theorists assert that families must work together as one unit, and through this shared leadership and teamwork can find positive meaning in their illness while remaining resilient in the face of their illness.

Health care providers can play a prominent role in helping these families to assign meaning to their uncertainty of when or if, they (or their family member) will receive a liver transplant using the tenants and philosophy of Walsh's family resiliency framework. Health care providers can help families to make meaning of end stage liver disease and the time spent waiting for a liver transplant by identifying in the developmental and ecological processes that are occurring in the families lives during this time of uncertainty and illness. Both Mishel and Walsh identify that

strengths and weaknesses must be identified in order for individuals and families to work through the adversity that they face.

This study explored the lived experience of waiting for a liver transplant for both the individual and family caregiver for a small group (seven) of patients and their families. Both Mishel's uncertainty in illness theory and Walsh's family resiliency framework in combination with an interpretive phenomenology methodology may expand our understanding of how and in what way patients and families live out waiting, as individuals and in the larger family context. Since both frameworks focus on the individual and family unit, they were a natural fit with an interpretive approach informed by the work of Heidegger. Heidegger (2005) viewed the individual as co-existing with the world, not existing separately. Individual experiences are informed by the myriad of relational interactions that exist and play out at the individual, meso, macro and exo dimensions. Taking this combined view helped me to understand how it is these families navigate through the healthcare system and their lives while they wait for a suitable liver to become available. Ultimately, these theories gave me a lens in which to critically examine what my participants were sharing with me, and my own interpretations of this.

### **3.3 Study Method**

#### **3.3.1 Setting**

This research took place in Halifax, Nova Scotia within the Multi Organ Transplant Program of Capital District Health Authority at the Queen Elizabeth II Health Sciences Centre (QEII HSC). The Multi Organ Transplant Program of the QEII HSC is currently the only facility that performs liver transplants in Atlantic

Canada. 20 liver transplants are performed in Halifax per year (MOTP, 2013).

Although the program serves patients and families who live in Nova Scotia, Prince Edward Island, New Brunswick and Newfoundland, all recipients must come to Halifax for their initial assessment and transplant. All patients, with the exception of those living in Newfoundland, are required to travel to Halifax every 3 months for follow-up appointments. Patients in Newfoundland are followed in Halifax, but have their 3-month follow-up appointments with a hepatologist in Newfoundland.

Attempts were made to conduct these interviews during patients 3-month follow-up appointments in Halifax, however only one out of the seven participants were interviewed during this time.

### 3.3.2 Sample

Inclusion Criteria for participating in the study included the following:

1. Individuals actively listed on the Multi Organ Transplant Program official liver transplant waiting list.
2. Individuals with a self-identified primary caregiver, regardless of if this person is related, family or a friend.
3. Individuals living in Nova Scotia, Prince Edward Island or New Brunswick, who travel to Halifax every 3 months for their follow-up appointments.
4. Individuals at any point along the waiting trajectory on the liver transplant wait time. There will be no targeted wait time, as there are only 12-15 individuals actively waiting on the list at any given time.

5. Individuals who have been determined as being mentally and physically healthy enough by their Hepatologist to provide informed consent, and who are able to participate in a face-to-face or telephone interview,

Exclusion Criteria for participating in the study included the following:

1. Individuals who have been previously listed on the Multi Organ Transplant Program official liver transplant waiting list, but who are no longer listed.
2. Individuals listed for liver transplant but who do not have an identified caregiver.
3. Individuals who are living in Newfoundland that attend their follow-up appointments in Newfoundland.
4. Individuals who are unable to commit to participation in the research study.
5. Individuals who are non-English speaking.
6. Individuals who are identified (by the Hepatologist) to be unable to provide informed consent to participate in the research study, due to cognitive impairment (e.g., hepatic encephalopathy).

### 3.3.3 Sample Size

As phenomenology looks to explore phenomena with a group of individuals who have all experienced a phenomenon, a heterogeneous group that may vary in size from 3 to 4 individuals to 10 to 15 is considered adequate (Creswell, 2013). Morse (2000) states that studies using a phenomenological methodology can reach saturation with sample sizes as few as 6.

Morse (2000) suggests that qualitative researchers consider several principles when determining an appropriate sample size. These principles include the scope of

the study, the nature of the topic, quality of the data, study design. The broader the research question; the longer it will take for saturation of research findings. In qualitative research saturation refers to the point in data collection when no new or relevant information emerges (Given & Saumure, 2008). If the topic being studied is clear and information is easily obtained in the interviews than fewer participants are needed. In considering the quality of the data, Morse shares that if the data collected closely aligns with the research question, that fewer participants will be needed to research saturation. Richer data may be collected when studies include more than one family member or that look at one individual over a period of time as opposed to focusing on one individual at one point in time.

Given intent of this study was not to draw inferences or make generalizations about the phenomenon of interest of waiting for a liver transplant, I recruited seven participants (three patients, four caregivers). With many of the patients residing outside of Halifax Regional Municipality, and the limited number of individuals on the waiting list at any given time (approximately 10-15 patients from across Atlantic Canada during my recruitment), recruitment proved to be challenging. Additionally, interviewing both the family member and patient provided richer data on the experience of waiting than if I were to of interviewed patients or family members alone.

#### 3.3.4 Sampling Technique

Purposive sampling was used in order to recruit appropriate individuals into the study. Purposive sampling allows researchers to select individuals for study participation based on their particular knowledge or experience (Speziale & Carpenter,

2007). Meetings with both of the pre-liver transplant nursing coordinators and Hepatologists of the Multi Organ Transplant Program were held to inform them of the study, provide information for staff members and assist with study recruitment. Staff members (nurses and physicians) assisted with recruitment, during all individual's check-up appointments at the pre-liver transplant clinic. The patients and their caregivers knew all of these staff members who assisted with recruitment. A letter from the patients attending physician at the transplant clinic was mailed out and/or given in person to all individuals on the waiting list that informed potential participants about the study, and asked interested individuals to contact me if they were interested in learning more about the study or had questions. Posters were given to the staff members to placed in the offices of all of the liver transplant team members, the clinic waiting room and nearby restroom that highlighted the purpose of the study, study requirements such as inclusion and exclusion criteria and the time commitment required for participants. My contact information (e.g., email and telephone number) was included on the poster so that any questions, comments or concerns can be promptly addressed.

All interested individuals who contacted me were eligible to participate. I accepted patients and caregivers at any point in their waiting time for a liver transplant, as this provided varying perceptions of the waiting experience. Although the inclusion criteria stated that all patient participants must have an identified caregiver to be eligible to participate, the reality is that within the Halifax transplant program patients will not be listed if they do not have an identified source of social and caregiving support. Although six out of the seven of the participants were patient-

caregiver duos, it was not included in my inclusion / exclusion criteria above that both members had to participate. I welcomed the caregiver who wished to participate despite her spouse's inability to participate for health reasons. Allowing caregivers or patients to participate without their identified caregiver enriched the findings and helped to ensure fairness, as not all relationships function equally or normatively.

One might postulate that the waiting experience at three or six months may vary significantly from that at one year, therefore interviewing individuals at any point in time on the waitlist provided the opportunity to illuminate differences and similarities among individuals' meaning assigned to the experience of waiting across various points in time throughout the wait trajectory. Since the intent was not to infer generalizations about waiting, but to begin to understand how waiting is lived out and the meaning both patient and caregiver assign to the experience, multiple perspectives helped to inform future research directions or education informing practice change in light of the limited research on waiting within this population. This ensured fairness and principles of equity amongst the participants.

#### 3.3.5 Data Collection

The primary method of data collection was semi-structured face-to-face and telephone interviews with each individual and their caregiver. Six interviews were conducted over the telephone and one in person. All participants were given the opportunity to meet in person, but due to demographics and participant health, six of the participants choose to participant via telephone. I, as the principal investigator interviewed all seven of the participants, which helped to ensure consistency among findings. Each individual awaiting transplantation and their caregiver were



interviewed individually, to ensure participants felt comfortable, candid and open about their experience. Each interview lasted between 45 and 95 minutes and were audio recorded and transcribed verbatim to ensure accuracy of the information obtained. At the time of the interview, each participant was assigned a pseudonym of their choice, which helped ensure anonymity and confidentiality.

An interview guide was developed to assist with the interviews, however this was only as a guide, not as a strict tool, as that would not align with the study methodology of interpretive phenomenology. The interview questions explored the participants' perceptions of what it meant to wait and how this experience of waiting has been like for them. All of the interview questions were open-ended in nature to promote a conversational style interview between the participant and myself. These interview questions also included exploring challenges while waiting for transplantation, and their personal and family strengths that assist them during this time. The interview guide also consisted of prompts, which helped to ensure that the interviews focus on exploring the phenomena of interest of waiting. I did not stick solely to these questions, and new questions developed over the course of conducting the interviews, which is common practice in conducting interpretive phenomenological interviews.

I offered the participants the ability to conduct their interviews over the telephone. I made these permissible due to personal preferences, health, travel and time constraints. The majority of my participants lived further than two hours outside of Halifax, and choose to participate via telephone for their convenience. Although some consider telephone interviews to be inferior to that of face-to-face interviews as

it deprives the researcher of the non-spoken informal body language (Creswell, 1998, Sturges & Hanrahan, 2004), other researchers have found that telephone interviews increase participant's perceptions of anonymity (Greenfield, Midanik & Rogers, 2000). This increased anonymity has been found to increase a participant's ability to speak openly and candidly about a topic, as they may feel more relaxed (Yin, 2009). Other advantages to conducting telephone interviews include decreased cost and travel for both the participant and researcher, and the ability to reach a geographically diverse population (Aday, 1996). For these reasons, telephone interviews were deemed appropriate for use in this research, although attempts were made for the interviews to be conducted face-to-face. To help promote a comfortable, candid environment for the participants' participating over the telephone, their partner (patient or caregiver) were asked not to be present in the room during the interview.

In addition to conducting semi-structured, conversation style interviews with the participants, I also kept a reflective journal. In this personal journal, I documented my thoughts, questions, opinions, prior knowledge interpretations and inspirations, which provided further elaboration as the research unfolded (Thorne, 2008). I journalled directly after each interview to ensure that my thoughts and perceptions directly after the interviews are captured. Insights from this reflective journal helped with the interpretation of findings, as journaling helped to capture initial data from the interviews.

### 3.3.6 Data Analysis

The purpose of data analysis in phenomenology is to preserve the uniqueness of each individual lived experience of the phenomenon, while permitting an

understanding of the meaning of the phenomenon to emerge (Banonis, 1989). Interpretive phenomenology cannot be reduced to one set of procedural steps, however, it must offer an auditable and plausible account of the world it interprets (Benner, 1994).

Data analysis was conducted utilizing Heidegger's philosophical view of interpretive phenomenology and informed by the theoretical perspectives of the uncertainty in illness theory and the theory of resiliency. As a novice researcher, I drew on the work of Max Van Manen (1997) to guide me in data collection and analysis. Utilizing the principles of these researchers helped me to ensure the data analysis aligns with that traditionally done with qualitative research, more specifically that of the interpretive paradigm.

The goal of data analysis was to seek out commonalities and differences within the interviews, and then further group these into overarching, abstract categories of meaning (Creswell, 2013). Following each interview, preliminary analysis was conducted, as these interviews were current in my mind. Analyzing the interviews was done on an ongoing basis, and aided in making revisions for future interviews, while helping to uncover themes in the data (Van Manen, 2001, Creswell, 2003). This process of on-going analysis was helpful, as there were time gaps between interviews, given the geographical constraints and small number of patients on the liver transplant waitlist participants. All seven interviews were conducted over the period of one month, which was helpful in keeping the data somewhat fresh in my mind.

Following the transcription of each interview, the text from the audiotaped interviews were imported into NVivo 10, a qualitative data management package. This helped to organize, classify and sort information. The use of NVivo did not impact upon the researchers emersion in the research, as it was solely used as a tool to classify and arrange text. I re-read and listen to and the journal entries, while comparing each interview and journal entries to the others, utilizing the philosophical foundation of Heidegger's hermeneutic circle. The interviews and journal entries were analyzed together looking for commonalities and differences; the journal entries helped to provide initial insights into the interviews as they occurred. The initial data analysis process involved making accurate records and spending time immersed in the data, in order to develop a sense of the whole (Thorne, 2008). It is through this process of interpretation that I sought to give a greater, deeper meaning and understanding to the phenomena of waiting as experienced by the study participants.

Within the qualitative tradition, "grasping and formulating a thematic understanding is not a rule bound act, but a free act of seeing meaning" (van Manen, 1997, p. 49). A theme may be defined as the experience of focus, of meaning, of point, and that it is in the process of capturing the phenomena that one attempts to understand a phenomenon (van Manen, 1997). Themes differ from phenomena, as themes assist us to label and name the structures of existence (Van Manen, 1997), ultimately giving way to the phenomena being studied. In the end, the use of themes help us to describe, interpret and present the phenomenon of interest. I began my thematic analysis by searching for recurrent themes throughout the transcribed interviews and journal entries. To begin my analysis I moved throughout the

transcribed interview texts and my own journal entries, as this assisted me in developing new questions for future interviews. As Morse and Field (1995) assert, these themes may not appear to the interpreter during the initial interview; however as the researcher moves further into the data they may become more apparent.

Furthermore, my experience as a Registered Nurse and direct care provider aided in the process of data analysis. As a research instrument, I brought my experience as an acute care Registered Nurse working with patients experiencing a magnitude of illnesses, including those of end stage liver diseases. I value the use of research to gain evidenced based information to guide future clinical practice in order to improve the quality, efficacy and safety of care delivery for patients and their families.

Having worked directly with patients and their families who are donating organs and those who have received them, I have an appreciation and understanding of how important this gift of transplant is for both the recipient and donor family. The experience of working with the donor family provided me a unique lens into not only my experience and meaning of transplantation but that of donor families and those who wait for transplantation. At the same time, challenges exist, as researchers can easily use their own personal experiences to dominate participants, which forces participants into the pre-existing view of the researcher that is placed upon them. As a researcher, it was important for me to have an open, non-judgmental frame of mind when entering into data collection and data analysis to ensure that my own experiences do not dominate those of the participant. As a researcher, I reflected

upon my influence on the participant, which helped me to ensure that my experiences did not impact upon the shared lived experience of the participant.

### 3.3.7 Reflexivity

Aligning with Heidegger's view that one may not bracket out their experiences, I took into account my personal biases, values, and beliefs around waiting through reflexivity by considering how I was situated in the research study. Reflexivity is an on-going process whereby the researcher uncovers and "examines their own values, assumptions, characteristics and motivation to see how they affect the theoretical framework and review of the literature, design, tool construction, data collection, sampling, interpretations and findings (Eun-Ok, 2002, p. 115). Reflexivity is important for an interpretive phenomenological researcher to understand, as what matters is not just what the patient says, but how this resonates with the researcher (Sabo, 2009). As I entered into the research, I considered my preconceptions and pre-understandings of the experience and population I was inquiring about. My pre-understandings that came from working with organ donors, patients receiving transplants and patients who had previously received organs included the perception that organ donation positively impacts the lives of many. I held a pre-understanding and knowledge of the benefits of organ donation, and how, despite the tragic loss of one life, that others could be potentially saved. I came to this research with the strong personal and professional belief in organ donation and transplantation, and with the notion that patients awaiting liver transplant are vulnerable; psychologically, mentally and emotionally. It is through this reflection that I began to understand their experience, while moving throughout the hermeneutic circle of understanding and

inquiry. Using my own pre-conceptions and pre-understandings assisted me in using the hermeneutic circle of interpretation, as each of the experiences shared with me were reflected by me with my existing lenses from my past experiences. As a hermeneutic researcher, it is impossible to bracket out our experiences, notions, ideas and perceptions we hold, and impossible to suspend these from each interpretation that we make in our research. Therefore, all of my preconceptions and understandings of patients awaiting transplant influenced each and everyone of my interpretations of this population. At the same time, I was cognizant of my potential influence and made every effort to ensure that the final voices of the experience were those of the study participants.

#### 3.4 Establishing Rigor & Trustworthiness

Criticisms of qualitative research have largely focused on the lack of attention to issues of validation and reliability when compared with that of quantitative research (Creswell, 2013). Others have argued that qualitative research lacks generalizability to other groups of people, as it is highly influenced by the researcher and generates large amounts of data from few participants (Mays & Pope, 1995). To provide critics and qualitative researchers alike with the ability to demonstrate rigor in qualitative studies, Lincoln and Guba (1985) substituted the commonly used terms reliability, rigor and validity with the concept of trustworthiness. Trustworthiness as explained by Lincoln and Guba contains four aspects: credibility, transferability, dependability and confirmability. The term trustworthiness is used interchangeably with rigor or qualitative rigor, as it is viewed to be parallel with that of rigor. Lincoln and Guba offer a series of methodological strategies for demonstrating rigor in

qualitative studies (Morse et al., 2002). I describe below how I used these four values put forth by Lincoln and Guba to demonstrate rigor in my research study, while sharing the experiences of my research participants. Close attention was paid to maintaining and demonstrating trustworthiness, or qualitative rigor in my study, as this helped to ensure my findings are valuable and representative of the individuals in my study.

#### 3.4.1 Credibility & Transferability

Lincoln and Guba (1985) proposed that the credibility of a naturalist inquiry study involves the probability that the research findings would be proven to be credible if tested, and that the credibility of a study is enhanced when the participants of the research approve the findings identified by the researcher. To enhance both credibility and transferability of this study, I provided rich descriptions of the background and context of the study participants, as well as how I as the researcher viewed this as influencing their place in the world. I also provided detailed and descriptive notes as to how and why interpretations were made, and based on what information these interpretations were formed, which can be found in my findings chapters five and six. Semi-structured interviews with patients and caregivers served as the primary source of data collection, as well as my own reflective journaling. The second criterion described by Lincoln and Guba (1985) is that of transferability. Transferability refers to the research findings applicability in other contexts (Lincoln and Guba, 1985). In addition to helping to enhance credibility, providing detailed explanations of how and why interpretations were made helped to demonstrate the transferability of a study, as it helps the reader to decide if findings can be transferred



from one group of people to another. These detailed explanations were achieved by providing detailed explanations, my journal entries and participant background information, which helped to secure issues of transferability and ensure readers that some of the findings of this research could be transferred to other situations.

#### 3.4.2 Dependability & Confirmability

The third criterion described by Lincoln and Guba is that of dependability. The most common method of ensuring dependability in a research study is to provide an inquiry audit (Lincoln and Guba, 1985). An inquiry audit is comprised of raw data such as interview tapes, data analysis products such as journal entries, data synthesis products such as initial structuring of data themes, process notes from the researcher and materials relating to intentions such as the research proposal and personal notes about the researchers motivations and expectations of the study (Lincoln and Guba, 1985). An audit trail helps the researcher to organize and document the research, and allows researchers to trust the findings because of the emphasis on how I made my phenomenological interpretations. It allows the researcher to organize and document all stages of the research, which helps to ensure that the research process is accurate and traceable. To ensure my research process is reflective of the meaning given to the experience by study participants, I shared my documentation, journaling and analysis with my experienced supervisor, in addition to documenting these items.

To attend to issues of confirmability of my research, Lincoln and Guba (1985) suggest establishing and maintaining a confirmability audit trail. Similar to the dependability audit, a confirmability audit involves systematically recording the process in which the research is conducted. Through direct work with my supervisor

and supervisory committee I secured confirmability; by ensuring that I organized and maintained clear records of my interviews, research methods, data analysis and reflexive journal notes that could be easily followed by an outside perspective wishing to replicate the research process.

### 3.5 Ethical Considerations

Prior to data collection and recruitment, ethics approval was obtained from the Capital District Health Authority (CDHA) and Dalhousie University in Halifax, Nova Scotia joint Research Ethics Board (REB). This study adhered to the guidelines from the 2010 *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* to ensure that the study is ethically sound. In order to provide evidence that ethical considerations were carefully considered, I have described several of the ways in which ethical considerations were achieved and maintained through my research study.

#### 3.5.1 Consent Process / Recruitment

Pre-liver transplant clinic staff assisted in recruitment by (e.g., nurses, physicians) asking individuals currently on the liver transplant wait list if they are interested in learning about a study that may be of interest to them. There are two dedicated staff hepatologists and two staff Registered Nurses that work with these patients, therefore all of these staff that assisted with recruitment were known to the patients and their caregivers. A letter from the patients attending physician at the transplant clinic was mailed to each individual on the waitlist informing them of the study, asking them to contact me if they had questions or are interested in learning more about the study. Copies of the study advertisement were posted in the pre-liver

transplant clinic and in the waiting area to ensure that any interested participants are aware of the study taking place. Interested study participants were given a consent form along with the study advertisement and were asked to contact me to discuss the consent form and to obtain verbal consent if they wish to enroll in the study. Several of the interested participants asked the transplant program staff if I could call them, which I did to ensure all interested participants were given the information they needed. I did a final review of the consent form with all of the participants at the time of the interview, using a telephone consent form approved by the Capital Health Research Ethics Board for those participating via telephone and the standard informed consent form (Appendix C).

Upon contact from the potential participant, I reviewed the purpose, significance, potential benefits and risks, time commitment and voluntary nature of the study. I reviewed the informed the consent form with the interested participant in person at the time of the interview, and the telephone consent form with those via the telephone. This helped to ensure that the study participants could provide informed consent if they wished to participate, and that they understood their rights associated with participating in the study. Verbal consent was obtained from the telephone participants using the approved telephone consent script, however written consent was obtained at the time of the one in person interview with the one participant who participated face-to-face. Participants were informed that they would receive \$40 to cover a meal, parking and for their participation in the research study.

### 3.5.2 Privacy & Confidentiality

Participants were reminded of the voluntary nature of their participation in the study. Interested participants were informed that their own names would not be used in the transcribed interviews and that pseudonyms would be used to maintain confidentiality. Participants were informed that unidentifiable interview quotes and stories may be used in future publications, and that they could withdraw their consent to participate at any time with no consequences. Participants were told that they may withdraw their consent even after agreeing to participate or during or after their interview, for a period of time of up to four weeks after the interview.

Participants were assured that their participation (or lack of) would not affect the care provided by the transplant program. Conversations were had with both the individual awaiting transplant and their caregiver separately, to ensure that both individuals fully consented to the study, and that neither was being coerced to participate. To ensure that study participants understood the letter of invitation they receive, the posters and the letter of invitation were written at a grade eight-education level. All of the participants were read the letter of invitation aloud over the telephone, as this ensured that all potential participants fully understood the research study, and could give informed consent if they chose to participate.

Following completion of this Master's thesis, a copy of my thesis will be sent to each of my participants. The master list that connected these names with their true identity was and has been kept in a secure, locked location that only I have access to. These transcripts and master list will be kept for a minimum of 7 years, as per the CDHA REB standard of ethical practice. After the study has ended all of the study

information will be transferred to Research Services at CDHA, and will not be viewed by my supervisor or myself. All electronic documents have been kept password secured and locked, to maintain privacy and confidentiality.

### 3.5.3 Promoting Beneficence

As the phenomenon of inquiry is both sensitive and difficult in nature, special attention was paid to the potential risk for harm to study participants and their family members. Uncomfortable, painful and possibly emotionally distressing emotions did arise from speaking about their experience awaiting transplant, therefore I had pre-arranged for all participants (including the caregivers) to visit and/or contact the Multi Organ Transplant Program psychologists if the participant felt any negative or distressing emotions as a result of their participation in the study. The psychologist was informed of these interviews to ensure their availability to the participants. Interviews were held in a private and comfortable area that was not located within the same area of the hospital in which they attend their follow-up appointments. Although distressing emotions did not arise as a result of the interview for my one caregiver participant, I was prepared to spend further time with the participant for emotional support and to ensure minimal psychological harm and the potential for debriefing.

There were possible benefits from participating in my study that were outlined in the invitation to participate and REB submission. These potential benefits included an enjoyment of the participant sharing their experience and their personal story, a potential sense of psychological relief after sharing their story and the satisfaction of contributing to potentially improving the future experience of other individuals

waiting for a transplant in Atlantic Canada. These potential benefits did not negate the fact that there were potential psychological harms, however these benefits may have served as reason for some participants to enroll in the study, regardless of the potential harms.

### **3.6 In Summary**

This study explored how patients and their caregivers in Atlantic Canada lived out the experience of waiting for a liver transplant. The study employed an interpretive phenomenology methodology, while being informed by the theoretical frameworks of Mishel (1981) & Walsh (2006). The study involved three patients and four family caregivers, and involved an individual in-depth semi-structured interview. Data analysis was conducted using the principles of Heidegger and Van Manen, while ethical principles and qualitative rigor were kept at the forefront of the research to ensure the findings are both rigorous and ethically sound. My personal and professional pre-understandings as an individual and a Registered Nurse were used, while remaining open and non-judgmental to the voices, perceptions and experiences of the participants.

## **Chapter 4    Waiting For A Liver Transplant**

The purpose of this Masters' thesis was to uncover the lived experience of waiting for a liver transplantation for both patients and their caregivers in Atlantic Canada. This study involved interviewing seven participants; three patients who are actively listed on the liver transplant waitlist and four individuals who self-identified as the primary caregiver for an individual who was actively listed on the liver transplant waitlist in Atlantic Canada. A review of the literature showed that little is known about the wait for liver transplant for both patients and their caregivers. This served to reinforce the need for research into the phenomenon of waiting. Both the patient and caregiver participants in this study were eager to share their story and experiences with me as this was something they seldom had a chance to do. It has been my experience as a nurse that this is due to the nature of health care in our country, as we employ a biomedical approach that places more value on the biophysiological signs and symptoms rather than the lived subjective experience. This often leaves patients, caregivers and families without the time, space and or place to share their experience. The findings that emerged from this study help to provide an understanding of what it is like to be a patient or a caregiver awaiting liver transplantation in Atlantic Canada.

### **4.1 Participants**

All seven participants resided in either Nova Scotia or Prince Edward Island (see Table 4.1 & Table 4.2). Three patient participants had been waiting for a liver transplant between one month and two years at the time of the interview; all had been diagnosed with end-stage liver disease. Two of the three patient participants were

female and two of the caregiver participants were male. The participants were all of Caucasian descent and the patient participants had various diagnoses which had led to end-stage liver disease. The ages of the participants will not be disclosed to ensure anonymity of the participants, given the small number of individuals waiting for a transplant within Atlantic Canada. The small number of patients on the wait list further constrains a more in-depth depiction of demographics. All of the participants were married and in a heterosexual relationship. All participating caregivers were the married spouse of an individual awaiting transplantation, with six of the participants forming patient-caregiver dyads. A fourth caregiver's spouse did not participate for health reasons. Although the study did not aim to recruit solely spousal caregivers, their participation provided a unique perspective into the caregiving experience of caring for a spouse awaiting liver transplantation and experiencing a chronic, debilitating illness. This correlates with the findings in the literature review conducted, which revealed that spouses are the most frequent caregivers for individuals with a chronic illness.



**Table 4.1 Patient Participants**

<b>Age Range</b>	<b>Gender</b>	<b>Time Waiting</b>	<b>Husband or Wife</b>	<b>Location</b>
30-40	Female	> 6 months	Wife	Nova Scotia
60-70	Female	6 months – 1 year	Wife	Nova Scotia
60-70	Male	> 6 months	Husband	Prince Edward Island

**Table 4.2 Caregiver Participants**

<b>Age Range</b>	<b>Gender</b>	<b>Time Waiting</b>	<b>Husband or Wife</b>	<b>Location</b>
30-40	Male	> 6 months	Husband	Nova Scotia
60-70	Male	6 months – 1 year	Husband	Nova Scotia
60-70	Male	6 months – 1 year	Husband	Prince Edward Island
40-50	Female	< 2 years	Wife	Nova Scotia

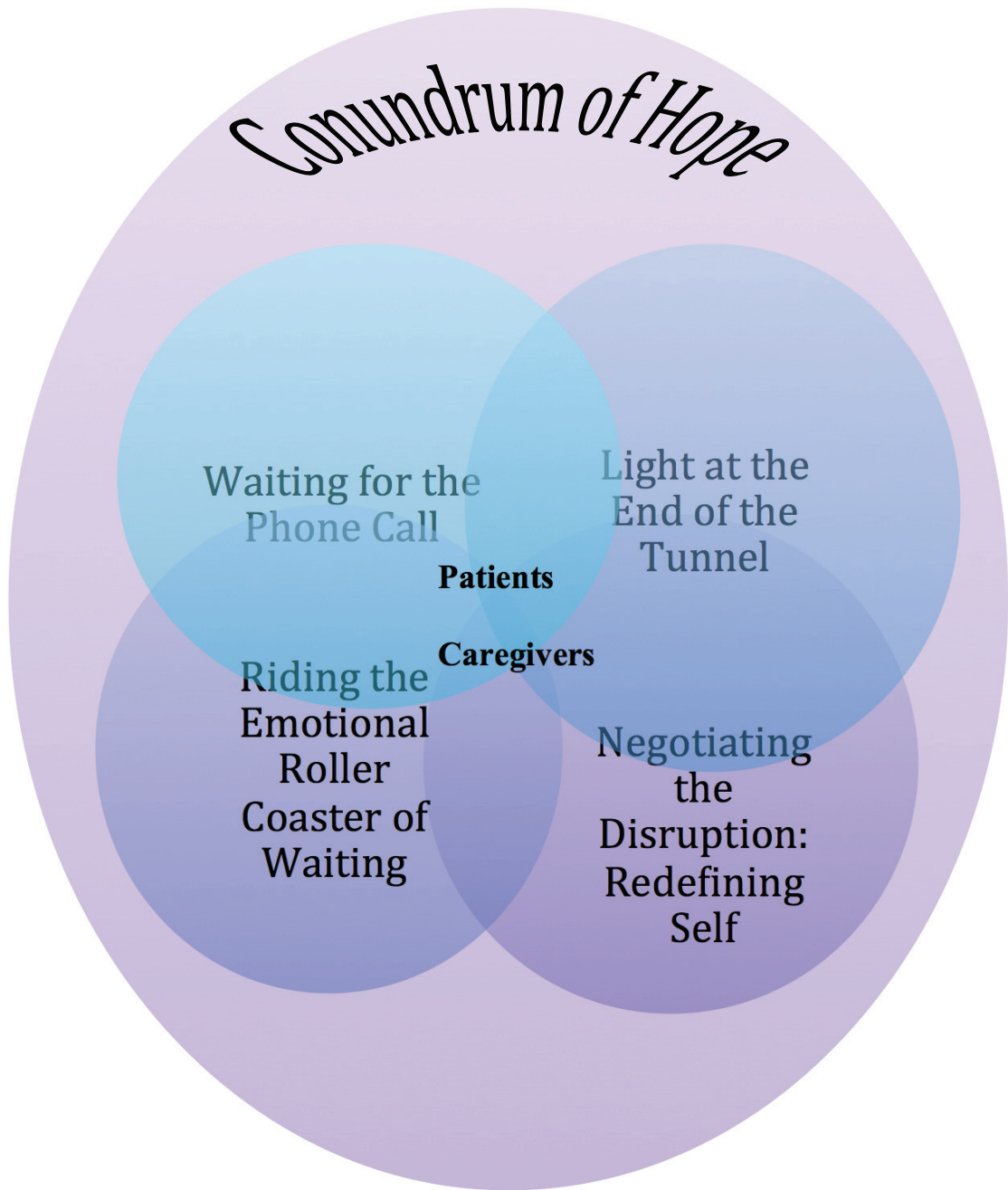
## **4.2 Introducing The Findings**

Having worked with patients and families who were involved in organ donation following an unexpected critical event, as well as the recipients of organ donation through my role as an operating room nurse, I became curious about the experience from the perspective of the patient and family who were waiting for an organ. I wondered how and in what way they lived with waiting. Did they think about receiving a liver every day? How did this wait affect their everyday life and the lives of those around them? In the asking “What is the experience of waiting for a liver

transplant for patients and caregivers in Atlantic Canada?” the following four themes emerged: Waiting for the Phone Call, Light at the End of the Tunnel, Riding the Emotional Roller Coaster of Waiting and Negotiating the Disruption: Redefining Self.

I will present the findings from the patient participants of this study in the following chapter, and the findings for the caregiver participants in Chapter 6. Although the experiences of the patients and caregivers were unique, these four themes: Waiting for the Phone Call, Light at the End of the Tunnel, Riding the Emotional Roller Coaster of Waiting and Negotiating the Disruption: Redefining Self reflected their overall experiences and were common to both patient and spousal caregiver. The overarching theme, the *Conundrum of Hope* resonated throughout all of the four themes. A visual reflection of the interconnection among all the themes is depicted in Figure 4.1. It should be noted that this is a visual depiction rather than a cause effect relationship among the themes and should be used to assist the reader as the discussion unfolds.

**Figure 4.1: Waiting For A Liver Transplant**



## **Chapter 5 The Patient Experience**

### **5.1 Introduction**

For patients with end stage liver disease requiring transplant, the wait is all consuming. The disease and associated wait impacts many aspects of their lives; their plans for the future, thoughts, emotions, perceptions and their relationships with family and friends. It is impossible for patients to escape the wait for transplant. For the three patient participants in this study, waiting was seen as a period of time, temporarily suspending their lives; it was not perceived as lasting forever. The meaning patient participants gave to waiting for a liver transplant emerged in four core themes: Waiting for the Phone Call, Light at the End of the Tunnel, Riding the Emotional Roller Coaster of Waiting and Negotiating the Disruption: Redefining Self.

### **5.2 Waiting For The Phone Call**

For both patients and caregivers, the meaning of waiting for a liver transplant brought with it many alterations to their everyday life. The patients identified the many changes that had been introduced to their lives since being placed on the waitlist. Patients spoke of waiting for the phone call telling them a liver was available, and that their wait was over. Repeatedly, the patients spoke of how being listed on the transplant list had changed their way of life. In particular, they spoke of the impact the telephone had in their lives. They felt as though the telephone, and the potential that it could ring with a moment's notice with news that a liver was available, controlled their lives. Several of the patients identified a sense of fear and excitement every time the phone rang; others questioned if they would be ready if this

was “the call”. Waiting for the call appears to be a dichotomy for the participants; on one hand there was an intense anticipation; a chance to regain health and happiness. On the other hand, receiving the transplant brought a sense of fear and a continual questioning of whether or not they were ready for this life-changing and life-threatening event. The ambiguous nature of the phone call pulled patients in multiple directions both emotionally and psychologically. For example, Josephine struggled with knowing there was nothing she could do to hurry her wait for transplant.

*..Just sitting around home and waiting and listening and trying to find out, when you're going to get your call.*

What stood out was the level of hopefulness patients maintained, despite the range of emotions generated while waiting for the call. Although all of the participants shared wanting to receive the transplant, for some the fear of receiving the transplant was as great if not greater than their desire for transplant. Getting the transplant brought with it the chance for renewed life, but with it also came risk. Undergoing the surgical procedure meant accepting these risks. All patients were aware of the significant surgical risks associated with liver transplantation, such as death, stroke and impairment.

In describing their wait for the phone call, patients spoke of how this was the hardest part of their experience, how this wait changed over time and how receiving this call was akin to a double-edged sword.

### 5.2.1 Waiting: The Hardest Part

For the patients in this study, waiting for the telephone to ring was often described as the hardest part of waiting. Knowing that there was nothing they could

do to make the call come was challenging for the patients. Waiting resulted in feeling on alert and anxious each time the telephone rang. Although we may take for granted the ringing of the telephone as a normal part of everyday life, this was not the case for participants. Waiting was something they could not escape or forget.

For example, Emma<sup>1</sup> identified the intense emotions that were relived every time she heard the phone ring while she was at home. With each call came the hope that a suitable transplant was available for them.

*Every time the phone rings, I'm thinking, oh, this could be the call.*

Emma, along with many of the others participants recognized that the call may not come as soon as they wished. They voiced how difficult it was to think about anything else each time they heard the sound of the phone. The sound brought intense emotions unlike any they had experienced before. The participants did not view these emotions as rationale, however these took over when the phone began ringing. Although they acknowledged that they would likely receive hundreds of phone calls before receiving 'the call', the loss of control attributed to the phone remained a key driver for intense emotional reactions.

For Josephine, the need to be constantly available and 'in range' for the telephone came with a price. She no longer enjoyed many of the activities and events she once had with her husband and family. Josephine described this as one of the hardest aspects of waiting for the call. This was a heavy price to pay; it effected not only Josephine, but her children, grandchildren and great grandchildren.

---

<sup>1</sup> Names have been changed to ensure anonymity and confidentiality

*You know, not being able to do what you want to do, type of thing. You know, you've got to more or less try to stay in the range in case you do get your call, stuff like that.*

For Charles, the constant waiting for the telephone call was especially tiring. He identified how the entire family was continually asking who was calling, and if it was the transplant program. Charles described experiencing frustration with his elderly mother and siblings as a result of their continual questioning. Their questions served to reinforce his situation – end stage liver disease. This constant questioning by family members and friends became a source of great stress for the patients – there was no escape from the reality of waiting. Any respite was often short-lived. Although the participants acknowledged that these inquiries were often from a place of concern and love, this did not change the fact that waiting for the call was a considerable source of emotional distress for the entire family.

*Did they phone, did they phone?" Well, if they had phoned, we would have let you know.*

Given that the patients in this study had been waiting for different periods of time for their transplant, there were differences in how the patients perceived the phenomenon of waiting for the phone to ring. Although many participants did not identify a change in their perception of hearing the phone ring, Josephine identified how the emotions of hearing the telephone ring were especially strong when she was first listed for transplant.

*Well, the first couple of days or weeks, it was when the phone rang, one of us would grab it. [laughs] And look at it. And my husband went away, like if he*

*went to the grocery store or down as far as the mall shopping or whatever, he kept calling back and asking if anybody called. And I said, no, nobody called. But now I just more or less say, you know, if they call, they call.*

Josephine acknowledged how her emotions changed over time, and how she no longer felt an immediate desire to grab the phone and check who was calling. The longer Josephine waited, the less hearing the phone ringing affected her. Over time, desensitization occurred suggesting an acceptance of the situation, adjustment or even resignation. Hearing the phone ring no longer carried with it the same degree of anticipation or fear as it once had; rather, it was simply that - a phone call that may or may not bring with it news of a transplant.

#### 5.2.2 Paradox Of The Ring – A Double Edged Sword

Several patients described the overwhelming emotions they experienced when the phone rang and the caller ID displayed that it was the transplant program calling. These emotions ranged from excitement, fear, and dread to impatience and anger.

*We have the caller ID on the phone. So sometimes, the phone rings and it says Capital Health or QEII on it, it's suddenly like, oh my god, is this the call? And am I ready for this? There's so much I want to get done before the transplant. But on the other side, I want to get the transplant done as soon as possible so I can feel better. So it's been... It's really... It makes me a bit nervous but also happy. But, if the phone rings, we're all wondering and waiting for the call. (Emma)*

For Emma, these phone calls from the transplant program became a source of stress and anticipation. They brought with them a sense of questioning and self-doubt



of whether or not she was prepared for the transplant. The possibility of a new liver came as a double-edged sword for Emma. She shared how she wanted and needed the transplant to get better. At the same time she had much to complete before receiving the transplant. Emma questioned whether or not she was ready to receive the transplant, ready for the risks associated with the transplant and if her family was ready for this significant change to their life. Getting the transplant would change their lives; they had become accustomed to living; a life they hoped would not revolve around waiting.

On the one hand there is a sense of urgency and happiness related to receiving the phone call; on the other, the idea of a 'right' time emerged. It appears that this 'right' time is when all tasks have been completed and the patient feels they and the family are ready for this enormous event in their lives.

### 5.2.3 In Summary

Waiting for the phone call signaling that a suitable liver transplant from a deceased donor was available emerged as one of the core themes surrounding the lived experience of waiting for a liver transplant. While telephones and cellular devices have become a regular part of everyday life, the concept of waiting for the telephone to ring with the call that a life-changing liver transplant was available was distressing for patients. The taken for granted notion of hearing a telephone ring was a source of extreme distress for patients, as they waited for a liver to become available. The patients shared that this meant being on constant high alert for the telephone to ring, and running to see who was calling. They also shared that this meant restricting the daily activities, travels and trips as 'the call' could come at any

time. The connection to the phone served as a source of imprisonment and restriction that impeded on all aspects of their daily life.

### **5.3 Light At The End Of The Tunnel**

Living with end stage liver disease and waiting for a liver transplant comes with endless challenges. These include physical, emotional and psychosocial challenges for patients and their families. For the patients in this study, strength and resiliency were imperative to getting through this time of uncertainty and numerous losses (e.g., control, ability to engage in routine day-to-day activities).

It was not surprising that all patients spoke of the actual transplant. They spoke of more than the transplant itself; encompassing getting the call, having surgery and walking out of the hospital with a new liver from an organ donor. The patients spoke of when they would receive the transplant, what would happen when they got the call, how receiving the transplant would impact their life and what it would mean for them. For patients, receiving the transplant meant the end of a long road of illness and an opportunity for renewed health. The patients saw their transplant as the light at the tunnel, which would bring with it happiness and health, two things they had been longing for since diagnosis and being placed on the waitlist. Ultimately, their hope and the idea of someday receiving the transplant gave patients the strength to continue waiting.

*I've had liver problems for almost 20 years now. There's finally light at the end of the tunnel. You know, that it's starting to happen, that's what the relief is. That I'm hopefully going to get better.*

For patients, the most effective coping mechanisms were frequently things

they found enjoyable, relaxing and therapeutic. These outlets had become more important than ever because of the high levels of emotional distress the patients experienced throughout their wait. For some, the challenge resided in the physical ability to engage in many of the typical stress-releasing activities, as Emma shared below.

*I like baking. And like I said, I do a lot of crafts. So when I feel up to it, I try to do a bit of that. And then I do a bit of housework when I can fit it in and if it's not something that's too demanding physically or too tiring.*

In contrast, Josephine found many of her previous coping mechanisms near impossible. For Josephine, the good days meant being able to do the things that were enjoyable, such as going for a walk, spending time with her children and grandchildren and going out with her husband.

*I just more or less watch TV and read a little bit and stuff like that. If I have good days or whatever, and my daughter cooks super, we go up there for supper. And my grandchildren, usually they're around. And I play cards sometimes with them.*

Changes to patients' physical and emotional abilities impacted the way in which patients were able to cope with the days spent waiting for a transplant. For many, this meant altering the way in which they usually managed and coped with difficulties in their lives.

### 5.3.1 Getting On With Our Lives

For patients, the wait for a transplant was perceived as a roadblock to moving forward with their lives. The participants not only spoke of receiving the transplant,

but also spoke of the desire to get on with their lives, and put this part of their life behind them. A transplant would enable them to do this.

*Hopefully I won't have to wait too long and then I can get on with my life and get better.*

For the participants, getting the transplant was seen as the key to getting better. Waiting for the transplant was the barrier to health. For Josephine, a healthier life was one where she would have the energy to do more with her time. Within the context of waiting for her transplant, Josephine saw her new life as full of limitations. For Josephine, a transplant meant not only an increase in health but also the ability to have a 'normal' life.

*...It will be nice to be able to get back.*

*..I'd like to be able to do more. But I try to keep pushing myself a little bit each day trying to get back up to where I was before but I haven't got there yet.*

Receiving a liver transplant was also about moving on. Moving on meant moving from the point of waiting for a transplant, to putting it behind them and even 'forgetting about it'. The idea of 'forgetting about it' was an interesting one; given how much of a focus waiting and liver disease had become for the participants. I found myself questioning whether or not the participants could ever forget about it, even if they did move on. Ultimately, getting on with their lives meant moving on, to a place where their life did not revolve around end stage liver disease or waiting.

Several patient participants spoke about the actual operation that they would have to undergo in order to receive their new liver when it finally became available.

For others the actual procedure appeared to be something left unspoken. The participants spoke of their concerns about the surgery, and also shared that these concerns were not necessarily things they voiced to their spouse. For many of the participants, voicing their concerns was more difficult than internalizing them.

*Because the more I think about it, the more I worry about things I shouldn't be worrying about. Like you know, like not making it through the operation or not having the outcome that I want after or that. So mostly the way I deal with it is try to...trying to distract myself or make myself forget about...not forget but try to not have those thoughts in my head.*

Although Emma described using distraction, she also highlighted her inability to push aside the potential negative outcomes. Distraction, used as a temporary escape, underscores one of the many coping measures that patients such as Emma utilized to move through the time spent waiting for a transplant.

In contrast, Josephine emphasized positive outcomes from the surgery. She continued to place emphasis on moving forward as a return to a life pre-liver disease and waiting for transplantation. This optimism and hope pervaded all the interviews, despite the possibility for declining health, rejection and even death.

*I try to keep telling myself that when this happens, it's going to work and I'll be better when I get a new liver. And things will be back up to, you know, normal hopefully.*

All of the participants were well aware of the potential risks they were accepting when placed on the liver transplant waitlist. Despite these very real risks, patients were overall hopeful that they would receive their much-needed transplant,

and that it would be successful. Patients felt that they needed to remain both hopeful and optimistic, as many felt that this would assist them through their wait. Others saw being hopeful as a choice, as either way they could not control the uncertainty that waiting for a transplant brought to their life.

### 5.3.2 The Need For Support

In order to be listed for liver transplant in Atlantic Canada, patients must identify as having adequate social supports. Without social support, patients are unlikely to have and maintain a successful transplant. Living with end stage liver disease and waiting for a liver transplant is not experienced in isolation. This period of waiting and the accompanying decrease in quality of life effects the entire family; inside and outside of the home. For some of the participants, the effect on the family was greater; particularly for those with young children. The family lived this time spent waiting in unison; it affected their daily activities and interactions with one another.

*..With my husband and my kids, because I don't feel well a lot, we don't do as much stuff as a family like activities, going out and things like that. And I know it's been because physically there's some things I can't do anymore.*

*(Emma)*

The patient participants in this study all lived with their primary caregiver; all of whom were their married spouse. They identified this support as vital to their ability to cope with waiting for their transplant.

Having a close-knit family was also identified as one of the most important sources of support for the patient participants. It was what kept them going, and got

them through the rollercoaster of physical and emotional experiences of waiting for their transplant.

*We're a really, really close family. And for me that's important. Like I can't even imagine not having my family there.* (Emma)

Despite the struggle to engage in family activities with her children and husband, Emma shared how her family came together around her to support her through her wait for transplant. Her family did not leave her feeling alone in her wait for her transplant; they provided emotional support through understanding her limitations, and recognizing her lack of control. Emma shared how despite her children's ages, they displayed a high level of understanding and compassion for their mother's disease. This compassion came as a source of relief for Emma, as she recognized how difficult her limitations were for her family.

*On the emotional side, you know, they've been helpful at understanding when I'm tired. That they don't say, "Well you're lazy, you're not doing anything with us," or whatever.*

Further evidence of the emotional maturity and understanding for families affected by liver disease and the wait for transplant was seen in Emma's narrative. Emma described how emotionally comforting it was for her teenage son to understand the financial impact of her wait for transplant. Her son's reassurance highlighted his high level of emotional maturity and how the wait for transplant had impacted his priorities. It became evident that for children of parents awaiting transplant, having a well parent mattered more than anything else.

*The financial part is the big one for us because our son is starting university next year. So we're trying to save up for that. But at the same time, we don't have a lot of spare money right now. So that's been a bit of that. But he's been... Our son has been really good and supportive and saying, "Like don't worry about that. We'll figure it out when you get better. We just want you to get better." So I think that one can help the other.*

Knowing what information and how much information to share with their family came as a source of stress for some of the participants. For Emma, it was difficult to decide how much to share with her young children; she wanted them to have an understanding of her disease, but did not want to worry them. Maintaining a sense of normalcy was a priority for the participants, especially those with young children.

*Sometimes I'm thinking maybe sometimes too much information or giving her too much information might worry her more. So we're trying to balance that so it doesn't. (Emma)*

For some families, withholding talking about the life changes occurring during the wait for transplant was easier than discussing them. Although Josephine knew her family was greatly affected by her disease and subsequent wait for transplant, this was not something they shared with her.

*I think it's affected them quite a bit. They don't really tell me. I think they have their sad days too.*

Additionally, Charles saw his family as affected by his liver disease and



wait for transplant. Like Josephine's family, this was not something that Charles' family frequently discussed with him. It appeared that the wait for liver transplant and failing liver was often viewed as the elephant in the room; always present but not discussed.

*Well, I'm sure it takes a toll on them. Neither one of the boys would be into debate over it or anything.*

On the surface, Emma enjoyed spending time with her family. However, deep down she knew she did not want to burden them with constantly travelling to care for her, as they had done when she was a child. Despite her worries, Emma's parents were committed to helping her through the challenges of waiting for her liver transplant and her ailing health. This support was highly valued by Emma, as it helped her to feel less isolated from her family and their busy daily lives.

*And my parents have been coming from [province] quite a bit. So they've been staying here when they come, sometimes like a week or 2 at a time. And they always, say, "if you need me to stay longer, we'll stay longer. Or if you want to come and spend time in [province], that's great, we'll be there".*

Families of all ages and developmental stages are affected by one family member's wait and need for a liver transplant. No family member is left unaffected by the need for transplant, despite the patient and caregivers best attempts to limit the effect.

The support and continuous and guidance from spouses was a source of strength for the patients. It extended beyond the physical aspects of caring to encompass the emotional, psychological, and day to day routine of life. In the

example below, Emma described just a few of the things her husband did, and acknowledged how caring for her caused him a great deal of stress.

*My husband has taken on a lot more things around the house. And on the other hand, because I'm not working, my salary has been cut. So he's kind of trying to compensate for that. So I think it's putting a bit more stress on him. And hopefully not too much. But he has been dealing with it... He has been like really great about all of it. He's been a great support.*

Charles also regarded his spouse as a tremendous source of strength and support, as he described in the example below.

*And I'm less of a... My wife is quite tolerant of me sometimes. But without her stability, I don't know what I'd do.*

Knowing that they were an integral and much needed contributing part of the family, as both a parent and a spouse helped to ease the burden of waiting. Feeling needed and appreciated within the family unit encouraged them to focus on living life. Furthermore, it helped them to fight harder to get better and stay as healthy as possible in preparation for transplant.

*I would say my family is the biggest part of it. I mean I just want to get better to be able to spend more time with them and be able to do more with them and, you know, just... I'm not, like I said before, I'm not done leading my life. There's a lot of things that I want to experience. So I'm just kind of looking forward to putting this behind me.*

For Emma, being needed by her children was a source of comfort and

empowerment. Knowing the important role she played in their lives reassured Emma that despite her illness and associated limitations, that she was still very much their mother. Her children helped Emma to feel that regardless of her illness that her role as their mother could not be replaced, and this helped to give her strength as she lived through the wait for transplant. Although this was not done intentionally by her children, Emma felt empowered by these words and actions; giving her strength and courage to carry on through her wait for transplant.

*My son has been... Well, both my kids but mostly my son has been... It was not even talking, he just has a good effect on me. It's been like that since he was a baby but even more so now that I need that support. (Emma)*

*If I have good days or whatever, and my daughter cooks supper, we go up there for supper. And my grandchildren, usually they're around. And I play cards sometimes with them. (Josephine)*

Children and grandchildren were also perceived to be sources of tremendous strength for patients in this study. Wanting to be there to watch their children and grandchildren grow up gave the patients hope. The desire to be there to watch their children and grandchildren mark various milestones was important and something tangible to hold onto, even worth fighting for.

*I have lots of reasons to have the strength to go on. I have a wonderful wife. I have the grandkids. That gives me hope. My sons. (Charles)*

The need for significant family support was described by all of the patients in this study. This support came from many different family members; spouses, parents and children. This ultimately left the patients feeling empowered, and as if they could

get through their illness and subsequent wait for transplantation. The potential also exists for the alternative to occur – for patients to rely on others for all aspects of their care and become completely dependent. The potential for infantilizing, a loss of control when one needs to rely on others for everything that we take for granted as part of being an adult could occur, as patients are so heavily relying on others for their well-being. Maintaining this balance could be difficult for both patients and caregivers, as they attempt to negotiate their roles as ‘patient’ and ‘caregiver’.

The reality of living with end stage liver disease was a reduction in or complete cessation of activities outside of the home. Many of these patients no longer had the energy or interest to participate in their social networks or activities they once considered enjoyable. However, the lack of engagement was viewed as temporary; once they received their transplant, they would be able to return to their social and recreational activities and a sense of freedom from the burden of waiting.

In comparison to the two other patient participants in the study, Emma was much younger and had been working outside of the home until recently. Having social support outside of the home was regarded as a great source of strength for Emma; her days home alone were long without her husband or children. Emma took strength from her network of colleagues and friends who were there for her regardless of the day or night or what was going on in their lives.

*Because I have such a great group of friends and family, a lot of times it makes me feel better. It makes me realize how lucky I am to have everyone.*

*There's always people in worse situations than me. I'm blessed to have what I have, and just enjoy what I have.*

For many, the need to rely on others for support and strength was something new. Although the support was constantly present, asking for it not an easy task, as they did not want to burden others with their needs or problems.

*It's hard because I like to... It's kind of funny too but I like to... I'm used to being the one who's there for my friends. So it's hard for me to go ask for help for support sometimes. So that's been a bit hard for me to admit that at this point, yes, I do need help and stop feeling like that and let them help you when you need it, you know.*

For many of the participants, it was easier to avoid discussing the troubling emotions of feeling a burden to their family and friends. Reassurance that this was not the case helped, but was especially difficult, if they were usually the shoulder others sought out.

*A couple of them, I told them that's how I feel but some other ones, I haven't. And I know if I did tell them that they would feel like, "You're crazy. You don't know what you're talking about. And don't worry about that," and things like that. But yeah, it's been hard on that side because like I said, I prefer being the one helping others rather than having them help me. (Emma)*

At the same time, participants did not want the focus of their relationships to be their illness, which led to challenges with how much to share.

*It's good to have people around either that... I say I don't like to bug them with it but some people will say, "Let's have a cup of coffee or a cup of tea and just chat. And you just let it all out." So that's good.*

The participants talked about the various types of supports they had throughout their wait for transplant. For patients, supports were imperative to their wait for transplant; without these they saw the wait as impossible. Unwavering support from family members was especially important, in particular the support from their spouse, parents and children.

### 5.3.3 In Summary

The Light at the End of the Tunnel emerged as one of the core themes in this study of patients awaiting liver transplantation. For patients waiting for a liver transplant, being placed on the transplant and getting the transplant was seen as the light at the end of the tunnel. During this wait, it was imperative to identify sources of strength in their lives. It was through the many supportive individuals in their lives, that they were able to cope with the emotional and physical turmoil associated with end stage liver disease and the wait for transplant. Sources of strength came from many different avenues for the patients, their children, spouses, parents, co-workers and social networks. Remaining hopeful that they would receive their transplant; the light at the end of the tunnel helped patients to continue on with their arduous wait. Ultimately, this theme, the Light at the End of the Tunnel speaks to the arduous wait patients have and how important significant sources of support are for the participants as they wait for transplant.

### 5.4 Riding The Emotional Roller Coaster Of Waiting

For the patients and caregivers in this study, living with end stage liver disease and awaiting transplantation carried with it a myriad of emotions. Many of these emotions appeared to arise directly out of the experience of waiting. Further, the

emotions affected their day-to-day lives, frequently constraining their activities. For patients, this was not unlike riding a roller coaster; filled with ups and downs that were unexpected and uncontrollable.

*Some days, it's frustrating. It's a lot of emotional days. But mostly it's just the waiting... The emotional part of it I find difficult. And hopefully that will be better after.* (Emma)

Waiting, and the ensuing emotions challenged all members of the family. Learning to manage and cope with the emotional aspect of waiting was identified as the most difficult to come to grips with. At the same time, all of the participants in this study remained continually optimistic and hopeful for a positive outcome.

While waiting for their liver transplant, patients experienced a variety of emotions that impacted many aspects of their daily lives. The patients described learning to live with the emotional aspects of waiting, a change in their images of self, how their liver disease affected the entire family, how they coped with the emotions of waiting and how the transplant program assisted them in their coping.

Waiting for a liver transplant is a dynamic, unfixed time for caregivers, patients or their families. The experience of waiting changed from day to day for the patients. The only constant in this state of flux was the uncertainty that waiting brought to their lives. Being placed on the transplant list came with a sense of joy and sadness for patients. Getting placed on the list meant moving toward health and improved quality of life, but it also meant accepting that their liver disease would not change without a life-saving transplant from a cadaveric donor.

#### 5.4.1 The Donor: The Ethics Of Goodbye

While all the patients in the study knew that the only way in which they would recover from their end stage liver disease was a liver transplant, for some this was a reality that was difficult to accept. The participants knew that in order to receive a liver, another family had to say goodbye to their loved one. This was extremely difficult for the patients to accept; they imagined what it would be like for these families to unexpectedly and tragically lose a family member. This situation was complex, placing the patient in the middle of an ethical dilemma – the wait for a death in order to have life. Although none of the patients explicitly shared they were hoping for another person to die to donate their liver, negative feelings were described by each of the patient participants. The very nature of how they would come to receive their liver was distressing and especially difficult. Charles recognized that new medications were no longer an option; his only recourse for a new lease on life would have to come from an organ donor.

*I know that they just don't have a recipe for them, and someone has to die to cure you. Which is... It's soul searching, I guess.*

For Charles, knowing that someone had to die for him to get better was soul searching. This made Charles reflect on his current life, his attitudes, his goals and the life he has lived, while thinking of the life that was lost. Ultimately, Charles saw the donation of someone's liver to him as a sacrifice that he would graciously accept in order to have a higher quality of life. He was also able to see this sacrifice in a pragmatic light, as he knew that one individual's donation could greatly impact upon another individual.



For other patients, the idea of someone dying in order to receive a liver was a difficult reality. For Josephine, the concept of someone dying in order to receive a liver was difficult to speak of. It immediately evoked an array of emotions for both the donor and recipient families. The concept was about grief and loss as well as about a life regained; something Josephine preferred not to dwell on.

*Just knowing about the family, And what they must have to go through.*

Patients acknowledged the tragic way in which most individuals become organ donors and further shared the emotions associated with knowing that another had to die in order for them to receive a liver. Reflecting on this led Charles to turn introspective – examining his ability to cope with the loss of another’s life in exchange for his. To acknowledge this loss, he would ensure that he cared for his transplant and grieved for the person who gave it to him.

*I don't feel great about it, not individually. It's just for me to live,  
someone has to fall down the stairs with an aneurism or something.  
And I guess I grieve for their loss. That's really what I think about.*

For those awaiting transplant, acknowledging that the loss of a life was the only recourse for them to regain their life, was insufficient to mediate distress. Recipient families recognized the intense pain that donor families find themselves in. To consider, in the face of loss, the decision to donate an organ cannot be an easy one. Participants in this study attempted to place themselves in the position of the donor family and the many emotions they would have experienced. Doing so was emotionally draining; at the same time, this helped them to cope, deriving comfort from the act of donation.

Patients waiting for a liver transplant all thought about where their much-needed organ would come from. For these individuals, this meant thinking about the usually tragic, unexpected death; often from an intracranial bleed, head trauma or suicide that renders an individual brain dead thus able to be a full organ donor donating their liver. The participants described how knowing that something tragic must happen to another and their family in order for them to receive the liver they had been waiting for was a very difficult reality, which many chose to think as little as possible about. This reality leaves recipients and their families feeling morally and ethically distressed as evidenced by Charles' quote above; they are ultimately waiting and wishing for their liver, which can only come through the death of another. It was through reassuring themselves they were helping the donor and the family with living on the legacy of the donor that helped them cope with knowing the tragedy and sorrow that this family would be experiencing.

#### 5.4.2 The Transplant Team

The participants shared how valuable reliable first-hand information was from the staff of the transplant program, and how unreliable other sources such as the Internet were at informing them of their health condition. This knowledge both informed them and reassured them, as they navigated through their lives while waiting for their transplant to become available. The health care providers at the transplant were not only a source of valuable medical information, but they were also seen as a source of emotional support.

*And I know that if I don't have the answer for something, I can easily just call and usually they'll get back to me the same day or within a day two with*

*answers or contact the persons that might have answer for my questions. Or If I'm feeling bad, if I'm feeling emotional or physically drained, I know there's always somebody there that can help.* (Emma)

The nurses with the transplant program were identified as one of the most important sources of social support that helped guide the participants through the emotional turmoil of waiting for transplant. For Emma, the relationship she had developed with the transplant nurse coordinator offered assurance about her physical and emotional well-being.

*And every time there's a worry about anything, even if it's not about my health issue, like if it's I'm feeling emotional or things like that, they've been.. they always get back to me almost right away.*

Although these relationships were professional therapeutic relationships, they were valued highly. In some instances the relationships were regarded as important as the friendships and social relationships outside of the transplant program.

#### 5.4.3 In Summary

The wait for transplant was mentally, emotionally and physically challenging for patients. Awaiting transplant was a roller coaster ride filled with unexpected ups and downs. The many emotions associated with waiting for a transplant made it impossible to escape the reality of end stage disease and need for a transplant. It is not unreasonable to expect such an array of emotions from the highs of regaining a new life through the lows acknowledging the many losses arising out of end-stage liver disease. As vivid as these emotions were for the patients, they recognized that their liver disease was a family disease affecting all of those around them. Coping with

these emotions effectively became a priority; it was only through coping and the management of these emotions that the patients were able to move forward in anticipation of the transplant.

### **5.5 Negotiating The Disruption: Redefining Self**

Waiting for a liver transplant meant living with significant changes to their lives. For the patients in this study, routine life no longer existed, but was irrevocably altered as they came to terms with the many disruptions in their life. Patients had to learn how to negotiate disruption and uncertainty. Unpredictability was a common feature, one that must be integrated as they redefined their sense of self. The ability to adjust was compromised by the many limitations including the physical and emotional. The patients not only had to accept the many unwelcomed changes in their own life; they needed to negotiate the changes occurring within the family including roles, responsibilities and relationships. Reflecting on the myriad of changes led to a re-evaluation and setting of new priorities.

#### 5.5.1 Loss: Images Of Self

One of the greatest challenges individuals faced with waiting for a liver transplant was navigating through the days in which they could not help but feel sad, depressed and uninterested. Participants in this study often experienced distress. For patients, feeling sad and having negative thoughts came from the imposed limitations and changes in lifestyle brought on by advanced liver disease. Waking up each day unable to do the things that they wanted or needed to was a constant reminder of their declining health. Their disease and subsequent changes to their lives left them feeling like a different person; someone who they never thought they would be.

*You sort of get down in the dumps a bit when you can't do anything.*

For Charles, being unable to look after the home and his wife left him with diminished self-esteem and self-worth. Charles struggled with these feelings, as he attempted to maintain as much independence as possible.

*Inferior. Yeah, I would say inferior.*

Josephine described how her disease negatively affected her perceptions of self. She highlighted how quickly her day would change. It was not uncommon for her to feel disgusted about herself, as she no longer looked at herself as a healthy, happy person as she once had.

*Disgusting and depressing. I just felt good and now it's happening.*

The change in self-perception came over time, particularly with the alterations to the patients' bodies as a result of treatment and their disease. For many of the participants, this disgust came from the inability to have adequate control over their bowels due to the lactulose medication they were prescribed for their liver disease. This lack of control and feelings of disgust had significant negative implications for patients, as they attempted to maintain a sense of normalcy.

*I'm sad more and I'm trying to work onto it but... Because I used to have interest in different things and going different places (Josephine)*

For many patients, sharing the difficult emotions or their diminished sense of self with others helped to lessen their impact. This underscores the need for adequate emotional supports for patients.

*Emotionally it's been good as well because I'm just... I think I'm... Even though I cry more and I have more emotional moments, I'm a bit more open to*

*sharing those thoughts so they don't get kind of stuck in my head and stress me from there without talking about it. (Emma)*

For patients with liver disease awaiting transplantation there were many losses both physically and emotionally. Many of these losses led to a change in self-perception and self-image for the patients, which often left them feeling emotionally and physically exhausted and unwell. For many, learning to cope with these emotions was a long process. The patients described the many coping mechanisms they used to get through this time, and described how it was often simply through expressing these emotions that they were able to cope.

Having end stage liver disease and awaiting transplantation led to feelings of a loss of self and change in self-image. As a result of their disease process, limitations and medication regime, many patients are left feeling detached from their former self, and not infrequently disgusted and depressed.

#### 5.5.2 How Things Have Changed

Living with end stage liver disease and waiting for transplant meant changes to many aspects of the patient's daily lives. Self-identity was challenged. Questions emerged as they attempted to navigate through this new life. For the youngest participant in this study, these changes meant having to stop working outside of the home. Emma described how devastating it was to stop working. For her, work was a source of enjoyment, a defining aspect of her life.

*I really like my job. And for me stopping my work a couple of months ago was really hard. But most of my days, it's like I don't do very much because like I say, I'm tired a lot. So some days I could spend half the day in bed. And even*

*if I do housework, I do 20 minutes of housework followed by a half hour nap.*

*It's hard because I'm used to keeping busy all the time.*

Having to stop working challenged Emma's perception of self. She was no longer the working wife and mother. Her previously busy, meaningful and productive days at work were now replaced with tiring, long days filled with boredom and fatigue. This led to loneliness and isolation, a disconnection from the person she used to be.

Waiting for the transplant also meant a change in social activities with friends outside of the family home. The participants described how different their social lives were. Empty social calendars became a common feature as they withdrew from contact with friends due to a decrease in energy and lack of interest. The patient participants shared that they did not want to be a burden to others in their lives; however this often led to isolating and limiting behaviours.

*I used to have a quite a bit more of time out with my friends. And because I'm so tired, I cannot do that as much. Sometimes if we do go out, I feel like they're healthy, there's a lot of things that they can do. So I feel sometimes if I go with them, it limits them to what they can do. So I feel like I'm kind of being a weight on their activities. So I tend to kind of back out sometimes.*

(Emma)

It was not only physical limitations that interfered with the lives of the patients in this study. Emotional limitations played a significant role in limiting social engagement. In an effort to avoid being perceived as a burden, they withdrew rather than "bringing down" those around them. Although Emma shared that her social

supports were always present, she described not wanting to “bug” them with her problems. She preferred that they continue to view her as the positive person she had been prior to her illness. Although the participants acknowledged the limitations and day to day reality of waiting for a liver transplant, they did not want their loss of health to be a focus of their social relationships.

*I tend to not keep in touch as much because I'm down a lot. I don't want to..., I feel like I'm complaining sometimes when I'm with people. And I'm a really positive person and I try not to bug people with my problems.*

Accepting how things had changed for the patients was a difficult task. It required acknowledging the many changes, accepting the changes and integrating them into their new life.

### 5.5.3 Loss Of Self - Physical Limitations

For patients with end stage liver disease awaiting transplantation, living with physical limitations had become a reality. These physical limitations effected many aspects of the patients’ lives, frequently in ways they had never imagined. The many changes of enforced limitations became a central feature of the narratives around waiting for a liver transplant. The patients shared a desire to live life the way they once had. As individuals, we often take for granted a life free of pain, fatigue, physical problems (e.g., loss of bowel control) and a reliance on the many medications to maintain life.

For example, Josephine shared how much she wished for her life to return to the way it was prior to her illness. She shared knowing that this would only happen if she was able to have a successful transplant.



*I'd like to be able to get up in the morning and not feel sick. And be able to come and go the way we used to. You know, get up in the morning and get ready for the day, and go out and... If the grandchildren got something planned, you can go to it.*

Being able to wake up each day and not feel sick was a dream of most the patients. Feeling unwell clouded and painted the tone for each day.

*There's a lot of chores around the house I can't do because like I start doing them and then I feel sick to my stomach. And I have to stop and lay down.*

(Josephine)

For Emma, not being able to do work around the house was especially hard to accept. She had only recently stopped working outside the home. The inability to perform the routine tasks of wife and mother came as a shock. Much of her life centered on napping to counter the profound fatigue.

*But most of my days, it's like I don't do very much because like I say, I'm tired a lot. So some days I could spend half the day in bed. And even if I do housework, I do 20 minutes of housework followed by a half hour nap.*

It was not only the physical symptoms of end stage liver disease that the patients had to contend with, but also the side effects of the medications to help manage symptoms, as previously mentioned. The participants described how ‘unforgiving’ the lactulose medication was that helped to clear the ammonia from their liver. For many, taking lactulose meant ensuring that they had quick access to a washroom 24 hours a day. Travel became limited as did time spent in public areas.

Charles poignantly described the challenges of taking this medication, which restricted his activities of daily life.

*I've had to wean most of those things out. And I have to be very careful where I go and how I go because the lactulose is not very forgiving. When it wants to go, it wants to go. And we're... Like since I had this bout last weekend, I'm taking 6 glasses of 30 ml of lactose. That's 6 times a day.*

The side effects of the medication that helped to treat their disease adversely affected their lives to such a degree that some felt it was worth the risk of skipping the medication to regain some resemblance of control in their life. For Josephine, taking the lactulose meant never being able to travel with her son, which was something that she just could not live without. The side effects were so debilitating and limiting, that Josephine was willing to live with the effects of not taking the prescribed medication. Taking lactulose left patients with little control over their bowel functions, and meant they had to remain constantly near an available washroom. For these patients, the longer they waited for their transplant, the more likely they were to require higher doses of medications; thus encountering more symptoms and side effects.

Waiting for their transplant and living with their liver disease, meant that the participants could no longer do the things they enjoyed. The patient participants could no longer do the activities they once planned and looked forward too, and this was a source of stress and disempowerment. These physical limitations made the participants feel lesser than they ever had in their lives, as they struggled to maintain sources of independence and tasks they could still complete.

*I mean I can't even use the snow blower. I can't shovel. I can't do anything. You know, things I enjoyed doing, it's difficult. I have to get my brother and his wife to come over and shovel out the driveway. We've always had someone to blow the main driveway out. But this has been somewhat difficult. You have to sit back and... Like the portable garage for the motorhome, to sit back and watch it shred in front of you and not be able to do anything. (Charles)*

Charles struggled with not being able to care for his home and his wife as he had for the many years that they had been married. He highlighted how he could not do tasks he once considered to be minimal, and how this made him feel as though he could not do anything. This was a personal struggle for Charles, and he shared he had to 'sit back' and watch his prized possession such as his motorhome and garden deteriorate. Watching others do what they considered to be 'their' tasks made the physical limitations harder, as they saw what they were unable to do as a result of their disease and the subsequent waiting.

Many of the changes to the everyday life of the participants came from the deterioration in the patient's physical and mental health. For Charles, this meant giving up freedom and independence outside of the home. Charles shared how his liver disease and subsequent encephalopathy restricted him from having his drivers' license. He described this as one of the worst aspects of the process of waiting for his transplant, as the longer he waited the more his health and life was negatively impacted.

*It came up once and I was always skirting around it. And actually it was probably one of the worst things of this process so far. But*

*everything happened fairly quickly. I bought the motorhome and the car or whatnot. So eventually I turned it in because with this condition, if you hit somebody, a pedestrian or anyone, you're never going to get your license back.*

The physical limitations wore on the patients as it limited their life and how they saw themselves. This change in self-perception was a challenge, as they could no longer be the person they once were. For Emma, the limitations were increasing at a fast rate, as she could no longer be the physically active person she once prided herself as being.

*For me personally it's my limitations of what I can do, and getting so fast that I can't do as much. Because I used to be a really active person. I used to go to the gym quite a bit. For now, I can't really go.*

All of the patient participants in the study spoke of the unrelenting fatigue experienced as a result of end stage liver disease. Regardless of how often they slept or how much they rested during the day, fatigue permeated their every waking moment. The constant fatigue left the patients exhausted, with little energy to partake in the happy moments of family life. For Emma, fatigue changed the way in which she could interact with her husband and her children. In order to interact and do things as a family now, they turned to less fatiguing activities such as board games.

*And physically because I'm so tired, I can't do that. But there's a lot of things. Because emotionally, I gain a lot by spending time with my family, we try to do activities at home. Like just during meals, like spending a little bit more time together instead of just eat and run. Or we've been trying*

*to play more board games with the kids or whatever just to be able to spend time with them.*

Even though family members tried to be accommodating, the day to day reality was a stark contrast to their previous life. It served as a reminder of the losses stealing precious time with family.

*Well, at home with my husband and my kids, because I don't feel well a lot, we don't do as much stuff as a family like activities, going out and things like that. And I know it's been because physically there's some things I can't do anymore. (Emma)*

Having young children made Emma's struggle with the debilitating fatigue unique in comparison to the other participants. Emma's children were of school age and enjoyed doing physical activity; however this was something Emma could no longer share and enjoy with them.

While waiting for their liver transplant, all of the patients identified that they experienced a lack of interest in many of the activities they once enjoyed. The patients acknowledged that their fatigue led to a decreased interest in spending time with friends outside of the home.

*It's... I ain't got that much energy and I just find that I can lay down and... If no one bothered me, I could lay down like all day and just sleep away. I just really ain't got much interest... interested in too much of anything anymore. But hopefully, you know, with the weather getting better and stuff, that will change too (Josephine)*

A lack of interest in doing things the participants once enjoyed doing was a shared experience. Charles also expressed a lack of interest in spending time with his male friends in the community. Although this had been something Charles had done for years, as his physical and mental health declined, he no longer felt like participating.

*I used to go to coffee every Tuesday... And it doesn't interest me.*

It appeared as if the patients feared they would be unable to live up to their obligations if they participated in these activities, again serving as a reminder of what they had lost.

*Yeah, I don't see myself as energetic or like to get too involved in anything. I'd just rather... I don't know, I just don't seem to have like the energy to get up and go and do what I used to do. (Josephine)*

The lack of energy and increased fatigue often led to an increase in emotions and psychological distress for the participants. Emma described how the fatigue led to feelings of self-pity and personal sorrow. It was on days like this, that Emma felt she could do nothing but feel sorry for herself and mourn the things that she could no longer do.

*And I used to do a lot of crafts but sometimes I just don't feel like it anymore because I'm too tired or, you know, I had an emotional day and I don't feel like doing anything other than just kind of sitting there sometimes with feeling sorry for myself.*

Despite their fatigue, lack of interest and energy, the patient participants maintained committed to doing as much as their health would allow. They remained

hopeful for the day they would receive their liver transplant and they would be able to participate in the live the life they desired.

Through their interviews, all three of the patients highlighted the hope that these physical limitations would only exist until they received their transplant. All of the patients were hopeful that the day would come where they could do these behaviors once again. They spoke of these limitations as being ‘for now’ or ‘this year’, highlighting that this would only be temporary.

Learning to accept that there would be both good and bad days was a challenge for the patients. They had to accept that there would be days where they felt they could do various chores and tasks, and there would be days when simply getting out of bed would be too much to handle.

#### 5.5.4 What Matters Now

Faced with a chronic illness; end stage liver disease necessitated significant change in the lives of the patients. This ranged from how they perceived themselves, to their abilities and outlook on life. In the face of incurable end stage disease that required transplantation for recovery, the participants shared how their outlook on life had changed. For some, this meant letting go of situations, events, or concerns that had previously been a source of stress and worry. For Emma, being in top physical shape was something she had always viewed as an important goal. After being diagnosed with end stage liver disease and placed on the transplant wait list, Emma’s outlook on her personal goals changed. Emma shared how being in top shape was no longer important to her; what was now important was being well enough to spend time with her family.

*Well, physically, I used to worry about if I didn't go to the gym and wasn't in top shape, I wasn't happy. But now as long as I can be to a level where I can do things and spend time with my family, I'm happy. If it gets better then it's even greater.*

The participants shared how the little things that they once worried about no longer mattered. For Emma, simple things such as how clean her house was no longer mattered; it was the time spent together as a family.

*Sometimes I would get stressed out about little things. Like oh my god, the house is a mess or, you know, there's so much to do that I'll never have time to do everything. And now I just tell myself, you know what, I'm going. And as long as I have my time with my family, those things that used to bug me, now they're like, oh, well, if it doesn't get done, it doesn't get done to do what I can when I have time. And whatever doesn't get done, so be it, it doesn't get done. . . As long as I can stay as healthy as I can and I have. . . I maximize my time that I can have with everyone.*

Life as the patients had once known it was no longer, as they had to learn to adjust and accept these new, unfamiliar changes. The participants struggled with these many changes; physical limitations, emotional limitations, fatigue and for some, a change in their priorities in life. Learning to live this new way of life did not come easy, as many of these changes restricted and limited the lives of the participants.

#### 5.5.5 Living Day By Day

The notion of living day by day and not planning for the long-term future was discussed by many of the participants. Patients shared how they no longer planned



their lives as they once had. Each day was a new day, a day that the participants were happy to have. Planning for the future was not a reality; rather, they lived in the present taking each day as a gift.

Despite the time they had already spent waiting for their transplant, all of the patients remained hopeful that their transplant would improve their health, and thus their lives.

*When I do feel better, hopefully the transplant will help to get rid of those other health issues or make them better. (Emma)*

The inability to plan for the future came with many challenges. The participants were at various stages of adjusting to the reality of no longer setting long term goals. Patients slowly learned to negotiate and navigate the uncertainty in their lives. As they came to adjust to living with uncertainty that waiting brought to their lives, they were able to regain some resemblance of control in their lives. For example, although long-term planning was not undertaken, the ability to plan short-term was something they had control over. These small successes offered a counterpoint to the negativity uncertainty can bring. It also fueled hope; hope for a healthier, happier future.

Although it was not clear exactly where this sense of hope came from, it became evident that being hopeful about the future was a choice that each and every patient made regarding his or her current situation. This continuous hope appeared to help the participants navigate through their daily lives spent waiting, as for them, they were waiting for something that would come, and would bring positive changes to their lives.

Living day to day was just one way in which the patients coped with end stage liver disease and subsequent wait for liver transplant. Due to their disease and the uncertainty of the wait for transplant, the patients saw living day to day as the only certainty in their lives. The patients no longer looked to the future as they had once had. Instead, living in the present, embracing each day as a success, helped to relieve the distress of a lack of future.

#### 5.5.6 In Summary

The patients awaiting liver transplant in this study found themselves faced with a myriad of changes to their everyday life. Life as they had once known it was no longer. They had to learn to adjust and accept these new, unfamiliar changes, and they had to learn how to negotiate this new life and the enforced changes. Within this, patients also had to learn to redefine themselves. Participants struggled with the changes; physical limitations, emotional limitations, fatigue and for some, a change in their priorities in life. Adjustment through negation did not come easy. Accepting this new way of life was a tumultuous process for the patients, as they had to learn to accept and focus on an altered level of control in their lives.

## **Chapter 6 The Caregiver Experience**

### **6.1 Introduction**

All patients on the liver transplant waitlist in Atlantic Canada must identify significant social supports prior to being placed on waitlist. These social supports are often referred to as ‘caregivers’ highlighting the level of care and support they provide to the patient. Most often these caregivers are spouses or family members who live in the home with the individual awaiting transplant. In this study, all four of the participating caregivers were the spouses of an individual with end stage liver disease awaiting liver transplantation. All four were married and identified themselves as the primary caregiver of their spouse. Regardless of their time spent caregiving, there were many recurring themes identified throughout the four interviews. Although similarities existed between how the patient and caregiver participants experienced waiting, caregiving brought with it many unique experiences, not experienced by the patients. These differences will be highlighted in this chapter. The meaning of the experience of waiting while providing care is reflected in four core themes: Waiting for the Phone Call, Light at the End of the Tunnel, Riding the Emotional Roller Coaster of Waiting and Negotiating the Disruption: Redefining Self.

### **6.2 Waiting For The Phone Call**

Caregivers described waiting for the phone call as one of the most difficult aspects of the experience of waiting for a liver transplant. Although patients also experienced waiting for the phone call as a distressing emotion, caregivers shared feeling ‘more responsible’ and a sense of duty to ensure the phone was answered in

case the transplant program was calling. As a result, caregivers appeared to experience higher levels of distress stemming from waiting for the phone call itself. This distress was due to numerous factors ranging from knowing that the only way they would be told a liver was available was through the phone ringing and the restriction that this brought to their life. It was also a result of the restrictions that waiting for the call brought to their life, such as ensuring they remained within cellular range service.

#### 6.2.1 Tied To The Phone

Caregivers described feeling limited by the act of having to constantly be at the other end of the line for the phone call 24 hours a day, seven days a week. This constant waiting and having to be able to answer the telephone at any given time came as a great source of stress for the caregivers. For Molly, this constant possibility of the telephone ringing signaling a viable liver was available meant someone had to be constantly at home available for the phone.

*..The waiting part itself was very hard., With the phone-wise, like you know, you don't want to leave the phone. (Molly)*

Caregivers experienced distinct changes to their lives. Waiting for her husband's transplant led to an altered social pattern for Molly, as she could not take part in many of the activities she once had with her friends outside of the home. This change in activities both inside and outside of the home impacted any sense of normalcy Molly had. She could no longer go about her previous 'normal' life as she once had, as that simply was not an option as the primary caregiver for her husband and children.

*I don't really want to drink just in case we get the call for the transplant.*

*Which I'm not a big drinker anyway.*

This constant wait for the telephone call also came at a price for Luke. Knowing that this call could come at any time on any day meant that their day-to-day activities were limited; they could not be more than a few hours from the transplant program in Halifax, and the potential liver. As a retired couple, Luke and his wife had previously travelled, particularly to visit grandchildren and other family members.

Similarly, Luke found waiting for the call to come to Halifax for the transplant as the most challenging aspect of the entire waiting experience. He described how the constant waiting for the call led to a new fixation - checking the caller ID to see who was calling in the hope that it would be the transplant program.

*It's just the waiting for that there call is what's the hard thing. About the hardest thing that I'd say, is waiting for the call to go to Halifax. Because like I say, everything time the phone rings, well, you know, you're always looking at it. And if it says QEII, I just run to the phone, "Here, the QEII is on the line".*

Lawrence also experienced this constant wish for the phone to ring informing them that a suitable liver was available for his wife. For Lawrence, this constant desire came from the notion that this phone call would begin the whole process of finally going to Halifax and getting the transplant that they had been waiting so longingly for.

*I wish that the phone would just ring and we'd say, okay, there's a liver, let's get going.*

Other caregivers shared how having to be near the telephone or within ‘range’ of the call, restricted their lives. They no longer could go about their lives as they once had, and could no longer travel, which was difficult for many of the caregivers to accept. As Luke described below, they had to be constantly aware of where they went, as it had to be within a short distance of the transplant program.

*We can't travel like we used to. I mean because you can't... If you were in Yarmouth and the phone call [came], it takes you 3 hours to get there. So mostly we stay around here. And you can't go. It's just something that you know that you can't do. So we just don't do it.*

Waiting for the phone call came with a feeling of being tied to the phone for many of the caregivers in this study. Caregivers felt confined and restricted by the wait that kept them home by the phone, yet each recognized this was an inevitable part of the wait for transplant.

### 6.2.2 A Family In Waiting – The Right Time

For caregivers and patients, the impact of waiting and liver disease was not experienced in isolation. The caregivers acknowledged that the entire family unit was waiting for the transplant. Families felt a need to be present every time the phone rang. Unlike many of the patient participants, many of the caregivers had to work outside of the home; despite this they described feeling tied to the house, in case ‘the call’ from the transplant program came. The telephone came to symbolize what might be – a new lease on life and an end to waiting.

Caregivers experienced the wait for the call differently than the patients, as many felt as though they needed to be the guard for the phone. Molly had been caring

for her husband for several years. She felt as if she was not only a caregiver, but also a guard. Molly struggled with the concept of waiting for the phone call, and found this to be both exhausting and tiresome on the mind and body. As her husband's primary caregiver, Molly took on the responsibility of answering the phone, despite the fact that he was fully capable of doing so.

*Well, it's exhausting. It's tiresome, right, because you're always on the guard for the phone.*

Molly went on to speak about how this constant looking out for and running interference impacted not only her life, but that of her entire family. She wanted to shelter her children from their father's illness. Molly did not want her children to worry, and was willing to take on the burden to spare the rest of the family. Taking on this burden has potentially negative implications for Molly, particularly if she is unable to share her experiences, emotions and feelings with others. Although several of her children were young adults, Molly still chose to protect them from their father's illness. Despite this, Molly discussed how even her school aged children took on this sense of urgency ever time the telephone rang, and how their first thought when the phone rang was a possible available liver for their father. Molly's experience highlights how waiting for a transplant not only affects the patient and caregiver, but the entire family unit.

*The phone is the biggest thing...If the phone rings, you're running to just check who's calling, right...In the house, that's a big thing. If the phone rings after 9:00 or 10:00 at night, when the phone rings, one of the kids will come in the room, "Was that the transplant place?" So really I would say for*

*everyone.*

Caregivers also spoke of how they both anticipated and dreaded the phone call that would alert them that a suitable liver was available for their spouse. On the one hand, caregivers could not wait for their spouse to finally receive the potentially life-saving transplant. Alternatively, they worried what this might mean, or what the associated risks were. This situation is paradoxical, as the phone call signaling that a suitable liver was both welcomed and dreaded. There was a sense of urgency and happiness related to receiving the phone call. At the same time, spouses spoke of a 'right' time to receive this call. For the spouses in this study, the 'right' time appeared to be when all tasks had been completed and everyone was ready for this life-changing event.

*We waited last year at my daughter's graduation, wondering if he was going to get the call. And we're praying that he didn't get the call because it was her graduation and prom. (Molly)*

Molly's comment highlights the mixed feelings about receiving the call; there was a desire to keep that part of their life separate from what may be considered the 'normal' aspects of life, such as celebrating their daughters' graduation. Underlying Molly's experience appears to be the desire to live a normal life again, where everyday family milestones and celebrations are experienced and celebrated, instead of living a life waiting by the telephone. Molly felt this might be achieved by having a better sense of where her husband was on the list. Placement on the list is important as it is equated with the likelihood of receiving a call shortly. This information then informs how and in what way they live out family life in the interim.



### 6.2.3 In Summary

Waiting for the phone call signaling that a suitable liver transplant from a deceased donor was available emerged as one of the core themes surrounding the lived experience of waiting for a liver transplant. While telephones and cellular devices have become a regular part of everyday life, the concept of waiting for the telephone to ring with the call that a life-changing liver transplant is available was distressing for caregivers. The taken for granted notion of hearing a telephone ring became a source of extreme distress and panic for caregivers and their families as they waited for a transplant to become available. The caregivers in this study shared that this meant being on constant high alert on the telephone to ring, and running to see who was calling when it did ring. They also shared that this meant restricting their daily activities, travels and trips, as the notion that ‘the call’ may come came as a source of imprisonment and restriction that impeded on all aspects of their daily life.

### **6.3 Negotiating The Disruption: Redefining Self**

For the spousal caregivers in this study, a significant part of their life was now devoted to providing care for their ill spouse as they waited for their transplant. For the caregivers caring for their spouse as they waited for a liver meant a change in their everyday activities. For many, this meant learning to do things they never dreamt of having to do and for others this meant fulfilling a spousal duty that they felt was expected of them as a loving spouse and partner. Being a caregiver meant having to negotiate the disruption waiting and caregiving brought to their life, and having to redefine themselves, as who they are had changed. Who they were, and how they

lived had changed drastically, which left caregivers in a constant state of change and uncertainty.

Waiting for their spouse's transplant changed many aspects of the day to day life for the caregivers. For Holly, the waiting period became filled with boredom, which stemmed from feelings of a life placed on hold.

*Yeah, I would say boredom. You're waiting for something so your life is on hold. Everything is on hold really. I think the boredom is more that we don't...yeah, that we don't do the...we're not able to do the things that we used to do.*

In the next example, Luke explained how different his life had been for the last few years since his wife had been ill. It not only meant a restriction and limitation of activities for the patients and caregivers, but also for their family.

*Like when we would go in the summertime, we used to take her to her grandson's. And they loved fishing. Well, she bought a 17' boat, [wife] did. And well, whenever the tides are right, we were out flounder fishing or mackerel fishing. We used to go all the time. So for the last couple of years, we haven't went because, you know, she just got so she was...she'd fall down and just nothing is going right.*

Similar to Luke's experience, Holly also shared how different her life was while waiting for her husband's transplant. For Holly, this meant a complete change in their pattern of daily living and the life they had once enjoyed together.

*Well, like I said, travel or even to go for a drive. [Patient] doesn't want to go for drives. He sleeps every afternoon. So our whole pattern of living has change.*

Caregivers found themselves faced with many changes to the life they had previously known. They had to learn to adjust, adapt and accept the changes they found themselves faced with, all while providing care and support for their spouse and family.

### 6.3.1 Caregiving; Not Optional

Although patients and caregivers shared many experiences, caregiving brought with it many experiences that were only experienced by the caregivers themselves. Caregiving for their ill spouse as they awaited liver transplant was not thought of as an optional task for the caregivers that participated in this study. For these caregivers, this was a part of their new everyday life and something that they now had to do. For both the male and female caregivers, this was now something they just did.

For example, Luke described how different it was to be in the opposite shoes that he once was twenty years ago after his heart attack. For Luke, caring for his wife was just something he accepted that he must do, just as she had cared for him twenty years earlier.

*Well, I think it might be because she helped me when I had the heart operation. I couldn't do nothing all that summer. And then after I had the heart operation, it was 6 months before I could do anything. And for a while, she even had to help me out of bed, you know. So I guess that's the reason*

*why I don't even think about that you might have to do this, you might have to do that. Yeah, I'll do it. It ain't no.. You know, I know that we've got to do it so we've got to do it.*

For Luke, caregiving for his wife was something he thought little about. He described how he didn't mind caring for his wife, and that the tasks he did for her and the home were things that had to be done. Dwelling on these roles was not something he felt was necessary. He fully accepted the need to become a caregiver and took the role graciously.

*Yes, it's different. But, really I don't even think about it. It's just I know it's something that I've got to do. I don't mind.*

Being the primary caregiver for a spouse awaiting a liver transplant was not something innate or a role that was time delineated – the end was a source of uncertainty, the never knowing when the transplant would occur and how this may or may not change their role as caregiver. For Luke and Holly, caregiving was described as a learning experience. This resulted in a complete role reversal within Luke's relationship with his wife. Holly described how, although her husband had been sick for over a year, she was still adjusting to being the primary caregiver for him while he actively waited for his liver transplant.

*I think I'm still learning to adjust to that [being a caregiver]. I think it's a learning experience and I'm just learning to accept that task. (Holly)*

Being a caregiver, regardless of age or gender came with a new set of roles and responsibilities for the participants. The caregivers no longer only negotiated their usual roles within the home and family, they now had the added responsibility of

looking after the ill spouse, the family and the tasks that the spouse had previously undertaken.

Two of the spousal caregivers in the study still had children living in the home under their care. These two caregivers in particular felt a significant change in their role in providing care for the entire family. This contrasted with the caregivers with grown children in the study. For Lawrence, this role extended beyond caring for the ill spouse, but also for his young children, a role his wife had assumed following the birth of each child.

*I would say stressful [being the primary caregiver]. I guess I think of it as like my duty as her husband but not as a requirement necessarily that that's the expectation. But I just personally feel that it's up to me to do everything I can. But there's other... Outside of her, there's family obligation. My daughter is in gymnastics. Getting her there and back, the travel.*

For Lawrence, providing care for his wife while she waited for her liver transplant was a source of considerable stress. He shared that now that his wife was unable to fulfill her previous tasks in the family, it was his job to take upon and ensure all of these tasks were still completed. Lawrence shared that as the head of the family he had to complete these tasks, regardless of the time and effort it took. Lawrence spoke of caring for his wife and his family as his duty, even though he acknowledged that others may not see this as a requirement, he felt it was for him and wanted to fulfill this duty. The children's many activities outside of the home provided challenges for Lawrence being the primary caregiver, given that prior to his

wife's condition worsening, they were both able to share the roles of ensuring the children made it to school, social events and their sporting activities.

Although Molly also had children living in the home with her and her husband, they were older which provided her with some much-needed help in caring for the home. In contrast, Lawrence had younger children who required more care and who were unable to share the duties of caring for the home. When overwhelmed with all of the roles and responsibilities, Lawrence found himself questioning whether he really could handle it all. The notion of having to 'be everywhere at once' described below highlighted how difficult it was for Lawrence to work full-time at his career and ensure their children's needs were accommodated and cared for.

*I sometimes may think what am I going to do by myself with the kids? Can I handle the house? Can I handle the kids' obligations? Can I be everywhere at once?*

The caregivers with younger children appeared to experience higher levels of stress. This is not surprising when compared to the caregivers without young children who found the additional support from adult children a source of support, reducing the heavy load of caring for the spouse and the home. For caregivers with young children there was more of a need to seek a balance between caring for the children, home, spouse and family making this experience more distressing and challenging.

Being the caregiver for their spouse awaiting liver transplantation meant also learning to become a healthcare provider. Given that all but two of the participants lived in a rural area that was a considerable distance away from the transplant program, the caregivers identified needing to learn how to provide the necessary

medical and nursing care that their spouse required. As the health status and physical abilities of the patients varied, so did the need for the caregiver to provide more comprehensive nursing care.

Molly described how much of a physical caregiver she had to become in order to care for her husband's complex, growing health needs. She likened learning this knowledge to learning to be a nurse for her husband. For Molly, this meant learning how to do tasks that were traditionally completed by Registered Nurses working in home care, such as changing her husband's ostomy pouch. Molly spoke of 'having' to do these tasks, although she did not mind doing so and was happy to help her husband with his numerous physical health needs resulting from his liver disease.

*And then I had to learn to be actually like a nurse to him. I had to learn how to change his pouch. I had to learn to...when your nose bleeds, I thought you just go like this. I had to learn how to put the ice on the back of his head. Like I had to care for him like in a way that a nurse would or somebody that...I had to learn how to give him injections. Like I had to learn a lot of things even just to take care of him myself instead of Home Care coming in, right. (Molly)*

In contrast, Holly described that her husband did not need as much physical care; but that she was needed in more of an advocacy role. This role in particular, meant ensuring her husband took his proper medications, ate the appropriate diet and stayed safe in their home; as her husband had frequent episodes of hepatic encephalopathy. Although none of the participants explicitly shared this, it appeared the marital relationship was changed by the wait for transplant. There appeared to be

a shifting of spouse to patient to child. The caregivers found themselves caretaking for their spouse as they once had their children; ensuring they were safe, healthy and cared for.

*Oh, he's pretty well able to look after himself except he can't drive. So I take him to all his appointments.*

*I remind him of things and guide him if I think he's not doing what he should or doing something he shouldn't.*

The caregivers shared their deep-rooted desire to help their spouse in any way they could, including with their physical needs. In contrast to Molly, Lawrence found the medical aspect of caring for his wife challenging and filled with ambiguity. Learning the medical aspects of complex liver disease was not an easy task, and knowing where to find the correct information proved to be even more difficult. For some caregivers, learning about the liver condition and disease was not as important, as many felt the nurses and physicians at the transplant program gave them all of the information they needed.

*What is it like? [caregiving] I'd have to say again, use the word stressful. Again, partly because I don't necessarily know what I'm doing. You know, I wasn't in the care business in a sense. I'm baking and finance, and taking care of money. I don't know medical needs. I don't know medication and what's wrong with the liver and why. It wasn't necessarily a job I signed up in a sense.*

The caregivers saw supervising and preparing medications as being one of the



more important caregiving roles. The caregivers understood the importance of these medications, and how without the transplant these were vital to the health and quality of life of their spouse. It appeared that many of the caregivers saw this as too big of a task for the spouse to look after on their own due to their declining health. This role was an important one in the overall care of the spouse; it came with the tangible affirmation that they were making a positive difference.

*Well, I try to make sure that he does what...takes his medication and that he stays in the house and doesn't go to do anything. He's been pretty good. He usually sleeps quite a bit. So that's good. But it's just a concern. (Holly)*

Holly shared her frustration in how her husband looked after his medication and diet when she was not present. She felt as if her time and education spent helping her husband was not recognized, as she described that it “didn’t go anywhere” when she was not present. Holly pointed out that this frustration was likely due to the fact that she spent all day, every day with her spouse, and that her own frustration with her husband led to her being upset with herself. This highlights the change in the relationship a couple experiences when one member is sick. Holly found herself as the caretaker for her husband, while her husband assumed the sick role.

Each of the caregivers overwhelmingly spoke of the changes to their everyday life since their spouse had become ill and awaiting transplantation. In these many changes, the caregivers spoke of the things that they had to learn to do since becoming the primary caregiver for their spouse, family and home. For many of these caregivers this brought upon feelings of fear, frustration and doubt. For others it came

with reward and a sense of accomplishment. The caregivers identified that they had no choice but to learn how to do these new activities and roles, given that they were 'it'. The participants highlighted the many tasks they now found themselves faced with, given that their spouse was no longer able to participate or do much of what they previously had.

In the following example, Molly demonstrated how she now had to maintain the household, a task that had previously belonged to her husband. Molly shared that she had to do all of the household maintenance, inside and out, as her husband was no longer able to do physically demanding tasks. It was not surprising that all of these new tasks, in addition to those that the caregivers had always done, led the caregivers to feel as if they were doing everything for the household and family.

*Like other than the driveway and clean the yard and paint. Paint the decks, that's something I never did before. There's lots of things that... Basically everything to run a household, I do it because he can't. There's little things he can do. Don't get me wrong, there is good days that he can get up and help with supper and he can help put the dishes away or he can help with anything, right. Not with the cleaning or anything but there is days that he can do, like cook and help us prepare the meals and stuff like that. But basically I do most of them. Well, the kids are older now too so they help, right. Yeah. But I do basically everything to run a household. That's something that I never done. Other than cook and clean, I never done anything. And now I'm doing everything. I went from nothing to everything.*

In addition to being her husband's caregiver, Holly spoke of the need to learn new tasks. In particular, the idea of having to do all of the driving, especially at night and in the winter, came as a challenge for Holly. The ability to travel the several hour drive to Halifax was vital in ensuring her husband remained on the transplant waitlist, and was able to attend all of his appointments outside of their province. Driving, although taken for granted by many was a significant source of stress for Holly, as it had always been her husband's job.

*I just kind of... I try to take this stuff a day at a time. A big problem I have is that I never was a winter driver and I avoided driving. And now I have to do all the driving, whether it's winter or not. And this has been a bad winter. So that's been the most stressful part of this winter, is the driving.*

For the caregivers, learning new tasks and having to do what their spouse was now unable to do was challenging, but was also seen as rewarding. The caregivers shared a sense of empowerment in learning to do these things that for many, they had never done. For these caregivers, learning to do it all came with hardship, but also a sense of personal satisfaction.

*Well, actually it's rewarding. It's very rewarding to learn to do that. Because what if I am... If he was feeling good and I did go to [town], if I had a flat tire, what am I to do if I didn't know how to do it, right? (Molly)*

For the participants in this study, being a caregiver meant having to take on the majority of household and family responsibilities both inside and outside of the home. For the caregivers, these new tasks were both challenging and rewarding; they

were things that they didn't mind doing, as they saw this as ultimately caring for their spouse and family.

### 6.3.2 The Need For Hope

All of the caregivers displayed considerable hope throughout their interviews. This persistent hope, despite the emotional and physical set backs became obvious throughout the interviews, as all of the participants shared feeling hopeful and optimistic that a successful transplant would come, and that life would be better. The participants shared that much of this hope came from feeling confident in the care provided by the transplant program, the devotion and care provided by their family members and from their faith and spirituality. Although not described in the interviews, much of this hope may come from the positive statistics, given that the majority of patients listed for liver transplant do make it to transplant, with successful survival rates immediately post-transplant (MOTP, 2012). Much of this hope also appeared to stem from the benefits of having positive thoughts.

Another reason for the hope displayed by the caregivers may be that the participants saw there being no other option. The caregivers spoke of the high level of uncertainty they experienced, and perhaps this optimism came from accepting the lack of control they had, and choosing to remain positive in their situation.

For many of the participants, hope was their saving grace. These participants remained hopeful throughout the waiting journey, despite the possibilities of complications from the surgery and organ rejection. Molly understood and acknowledged the risks associated with her husband undergoing his liver transplant, but was still able to see the future optimistically, as she shared her belief that he

would pull through the surgery. Furthermore, Molly described how she and her family would pray for a positive outcome when her husband does finally receive his transplant, but how she is at peace with the outcome. Despite this peace and acceptance described by Molly, it was evident that this uncertainty was present each and everyday. Although the participants spoke about the uncertainty of if, or when a transplant would occur, neither patients nor caregivers spoke about death directly. It appeared that although it resided in their minds, speaking of the possibility of death was too painful.

*Well, if he comes out the same... Well, we're hoping and praying that nothing bad will happen. So if he survives the surgery, if he comes out the same, well, at least he gave it a shot. He tried, they all tried, whatever. If it comes out being better, great.*

Caregivers saw their spouse receiving their transplant as the light at the end of the long tunnel of waiting, yet lived with the uncertainty of this 'in-between' period. The caregivers no longer viewed the future as they once had. They spoke of the notion of living day by day and not planning for the short-term or long-term future. Every day was a new day, a day that the participants were happy to have. The caregiver didn't know what the long-term future would bring; therefore only lived for the moment.

*I don't think about what's happening, what's going to happen or what I think is going to happen down the road. I cannot do that because I find if you plan anything anyway, it doesn't work out. You just take it one day at a time and just keep going forward though. Don't ever look back. Whatever happened*

*today, anything bad, don't look back on it. You're on a new day. It's a new fresh start. Every day is a blessing. Every day you wake up, it's a new day. And you just do that every day. And then try to drag all the good things out of today to carry on for you tomorrow. (Molly)*

The future was something Molly previously thought of and planned for in her life. Molly shared how she no longer planned ahead like she once had before her husband became ill. Molly shared that this was not because she did not want to – but because she simply could not. This highlights how the outlook and perception of an individual or caregiver can change during the distressing and difficult wait for transplant.

Like Molly, Holly also did not feel she could look beyond the short-term future of her husband getting his transplant. The caregivers all identified feeling trapped in the short-term, which highlighted how limiting waiting for the transplant can be on the primary caregiver. The caregivers lived in the moment, and at this very moment all that mattered was the present, not what may or may not come in the future.

*So I don't look beyond... I try not to look beyond the transplant itself because I figure that he's going to be so much better. And I've been told by people who had family members that had a liver transplant that they are so much better after they have it.*

Caregivers interviewed in this study remained hopeful that their spouse would receive the transplant, and that the future would hold a higher quality of life for their

spouse, themselves and their families for now and the future, as Lawrence shared below:

*I want to see that...her smile. I want to see her uplift, carefree self-back. You know, go for walks on the beach. Not necessarily see her do household chores. I mean those are just things that people do on a day-to-day basis. But she would probably take joy from carrying a basket of laundry, you know. [laughs] Just being able to be what she was before. To be able to enjoy a walk, to be able to enjoy laundry, to be able to go for maybe a run with the kids. I don't know if she would necessarily do that but to have the ability just to get up and do it.*

Similarly, Luke shared how he and his wife used to enjoy boating in the neighboring communities where they lived. Luke described hoping that they would get to enjoy this time spent together once again. The participants remained hopeful that they would be able to return to the activities they once enjoyed before their spouse was unable to participate due to their declining health.

*Hopefully we'll get the boat out in the water again. (Luke)*

For other caregivers, receiving the transplant meant a freedom to do things outside of their relationship with the patient, and outside of the home. This included relief from the constant worry every time they left the house, and having the ability to travel or go places without the ill spouse. These caregivers described how this would change their lives drastically and what this would mean for them. While caregiving for their spouse awaiting transplant, this desired life was simply unattainable. The caregivers now had the burden of caregiving 24/7, often without relief. The

relationship of wife / husband had drastically changed. The caregiver now found themselves taking on the caretaking role, which included supervision, education, caretaking and placing another's needs above their own. Although the caregivers did not describe their relationship as being changed, it appeared as though it had. This discrepancy may be a result of the societal expectation that spouses care for each other, and the hesitancy to sound as if they were unhappy or begrudged caring for their spouse.

*But just... If I was away for a couple of days, I wouldn't worry about when I call and she doesn't answer. I'd be thinking, okay, she's just not home. She's outside in the yard working in the garden; not, is she on the floor having a seizure? That stress would be gone. For one, I could feel that I could travel for a period of time, be it a couple of days or a week, without having to worry about what's happening at home or having to call her mom to come up from NB and say, I'm going to be away a few days, can you come up and keep an eye and make sure everything is okay? She's quite capable of living on her own when she's healthy. But I guess I'd be freed a little bit.*

*I guess it would kind of be liberating in the sense that, not that I feel chained.*

In the above examples, Lawrence refers to the ability to travel about the world without the constant worry of his wife, as leading to freedom. Although Lawrence shared his expectation that the transplant would be liberating, he also reinforced that he did not feel chained by his wife or her illness. This suggests that freedom, and



enjoying the many activities of life is restricted for not only the patient waiting, but the spouse / caregiver too. This freedom would be from waiting, in addition to all of the restrictions that caring for someone with end stage liver disease awaiting transplant brings to their lives.

### 6.3.3 What Matters Now

Caregiving for their spouse awaiting transplant came with it a change in perception and priority for the caregiver participants. Like the patients, the caregivers also experienced a change in their priorities in life since their spouses had been listed for transplant. What once had mattered to the caregivers, no longer mattered. Molly shared how the material things in life such as possessions were no longer important to her. What mattered now, was spending time together as a family; the little things.

*..I used to love rings. And every 2 or 3 years, I used to get him to get me another ring – anniversary or whatever. But that don't...Rings are nothing. I gave them all away and I don't want them. Like you know, this here brought a new meaning to life. Like you know, the big things don't matter in life no more. It's the little things. Like you know, for me and him to go for a drive, and he can drive, that's great. It's the little things in life.*

In particular, Molly described how her priorities had changed and how spending time together, anywhere as a family was most important. The money, the trips and the possessions meant nothing without family.

*The big things don't matter anymore. Maybe it will go back to being that way but I highly doubt it because we've been through too much to even think.*  
*[Talking about going on vacation to a warm climate] I don't care about any*

*of that. But before, I wanted to go. But like you know, what I want more is all of us to go as a family, to anywhere.*

Caregiving for their spouse led to a change in perception and priority for the caregivers in this study. The wait for transplant helped Molly to further realize the importance of her family, and how much the ‘little’ things truly mattered.

#### 6.3.4 In Summary

For caregivers, having their spouse listed and waiting for a liver transplant changed their perceptions of both of the short-term and long-term future. This meant that for many participants, the long-term future was no longer something they could plan for. The caregivers resoundingly described being hopeful about the future, and looked forward to living out this future, with their spouse. Although it was not clear exactly where this hope came from, it became evident that being hopeful about the future was a choice that each caregiver made with regards to their situation. Others felt there was no other choice but to be hopeful, as they had accepted that they had no control in if, or when their spouse would receive the transplant. This continuous hope helped the participants navigate through their daily lives spent waiting, as for them, they were waiting for something that would come, bringing positive changes to their lives.

#### **6.4 Light At The End Of The Tunnel**

The caregivers spoke of when their spouse would receive the transplant, what would happen when they got the call and what it would mean for them. They saw their spouse getting the transplant like the light at the end of the tunnel. Caregiver participants wanted to give of all of themselves to their spouses, which highlighted

the love and support these caregivers had. Lawrence discussed how challenging it was knowing he had a healthy liver, but that he couldn't share it with his wife in her time of desperate need. It was very difficult for him to accept that no matter how hard he tried, or how much he wished he could, he could not get his wife a new liver.

*What can I do about that? I know I can't give her my liver. I can't go get a liver.*

It was not surprising that all of the participants spoke of a transplant yet it was more than the transplant itself; it encompassed getting the call, having surgery and their spouse walking out of the hospital with a new liver. Lawrence shared why he felt that his wife getting the transplant was like a light at the end of the tunnel. For Lawrence, the transplant would be the light through all of the darkness and hardship that he, his wife and their family had gone through for the past several years.

*When a donor is available, we get the surgery. There's light at the end of the tunnel. It's just the goal to shoot for. The way I look at it, everything is going to be better when that happens.*

The caregivers spoke about the future, and although spoke of wanting to get back to their former lives, acknowledged that this might be different than it was previously. The participants did not know what this new life would look like, as they knew it would not be the same as their previous life. Both caregivers and patients acknowledged that the patient would not be the same as they once were physically, mentally or emotionally. In looking at moving forward in their lives and returning to normal, the participants discussed what this might look like. The participants acknowledged that returning to normal would not be a swift transition for patients or

caregivers, as the impact of their disease would not be alleviated the moment they received a liver.

During the interviews, the caregiver participants spoke more about their apprehensions about the operation, the risks and possible outcomes, both positive and negative associated with the surgery than the patients themselves did. The caregivers spoke of their concerns about the surgery, and shared that these weren't necessarily things they voiced to their spouse. For many of the caregivers, voicing their concerns would be more difficult than internalizing them. The caregivers attempted to "buffer" and protect their spouse; they did not want to burden their spouse with their emotions, feelings or thoughts. They felt as though their ill spouse 'had enough on their plate' without adding their own grief and emotions. This was a paradox for the caregivers; they knew it was therapeutic to share their feelings with their spouse. However, they wanted to protect their ill spouse from themselves, and wanted to focus all of the attention and efforts on the spouse; even if it meant neglecting themselves.

As the patients and caregivers in this study shared, the patient would not simply be cured of their liver disease and ailments immediately upon receiving the liver transplant. Many of these ailments would continue post-transplant, and these patients would be monitored closely. As a nurse, I found myself wondering how the participants would negotiate the patient remaining between the balance of 'normal and healthy' and the 'sick role'. Transplant patients fall outside of the traditional view of a sick patient, given that even after treatment, they remain closely monitored, tested and treated for life. As a result, caregivers of spouses with end stage liver

disease may find themselves being the life-long caregiver for their spouse, even many years post-transplant.

#### 6.4.1 Support Outside Of The Home

Caregiving for an individual awaiting transplant not only increased the need for locating and having support outside of the home, but also limited the ability to receive this support. The caregivers lived throughout the Maritime Provinces; some in rural areas, with others living near the transplant program. Although the caregivers did not speak of supports being inaccessible, it is reasonable to assume that those living further away from the transplant program have less access to health care resources. Many of the caregivers shared how demanding their lives were now that they had to care for the entire family, home and spouse. Despite being limited in their time spent away from the home or with their social networks, the caregivers shared how their family and friends did not abandon them during their time of need. Molly described how although she spent little time with her friends during the first two years of her husband's illness and wait for transplant, her friends remained in her life as a source of support and hope. Molly valued simple acts such as check-in telephone calls by friends and family members outside of the home; it was these acts that made a difference in her everyday life.

*Like now I'm starting to interact more. At the first, I was nervous to leave my husband. My friends are still my friends. They never... None of them ditched me or none of them stopped calling. We still do things. We still go out. Like I go out more this year than I did, like I said, last year. I go out with my friends*

*playing broomball or whatever. But a lot of phone calls. There's a lot of support.*

Family members living outside of the home also assisted the caregivers with care. They assisted with travelling to and from their appointments, and more importantly listening and helping them to understand all of the complex medical information shared with them. Caregivers highly valued and appreciated this support, as it lifted some of the burden from them. This type of support meant someone else could help them in understanding the information and instructions given to them. For Luke, having their daughter actively participating in all of his wife's medical appointments meant he could spend time away from home. Having his daughter up to date on his wife's condition meant he did not have to worry about his family being unfamiliar with his wife's complex condition in case something were to happen. This suggests the need for respite care to be available for these caregivers, which would help alleviate the burden experienced by these caregivers.

*So she knows that much about going to Halifax and stuff as we do because she goes with us. She goes down to Halifax on all of the trips. And she knows everything that's going on. My grandsons, both of them, they do whatever they can for their grandmother. So when I go away, I know one of them are around here somewhere handy, you know. If she needs them, all she's got to do is call and within, well I'd say within 10 minutes at the most, somebody is here.*

For caregivers awaiting liver transplant, the supports that gave them the strength to live out the days spent waiting for their transplant came not only from

their family and those living with them, but also individuals outside of the home.

While living out the days spent waiting, the caregivers felt that they had many people to turn to in their lives, particularly when in need. It was not uncommon for the participants to describe that despite their decreased presence within their friendships, communities and social groups, that these people remained sources of great hope, strength and resource.

*I'd say it's just my faith and my friends, and my family of course. Yeah, I have my son here and his family, and I make sure I get there to visit once a month. And I have a son in Kansas. And they call me and they text me and they email me. And I have a niece that's really good to me. She's good to both of us.*

Not wanting to be a burden was a shared experience between both patients and caregivers. Neither wanted to be seen as a burden on others, especially those living outside of their home with their own needs, issues or problems. Although the participants acknowledged caregiving for their spouse awaiting transplant was a challenging and demanding task, they did not want to bring their problems and hardships to the lives of others. Caring for someone with end stage liver disease was not something that most families or individuals did, and the caregivers recognized this. They did not want to bring any negativity into the lives of their friends and those around them, even if it meant not sharing what they needed too, as Lawrence described below:

*Sometimes I just feel like yes, I'd love to probably get things off my chest but I don't want to burden others with the situation. A lot of friends and neighbours, you know, they all know the circumstances. But if I don't see them on a daily*

*basis and I don't really want to go there with them when I do maybe run into them. Sometimes you hear people say, you know, I ran into so and so the other day, and they dumped their whole life story on me about they're always at the doctor's and they've got this going on and that going on, and they drive me nuts. You know, I don't want to be that person. [laughs] Sometimes I'd love to spill it but I don't want it to be annoying to others.*

Lawrence's example above highlights the need to share the experiences of daily life for caregivers caring for someone with end stage liver disease. This example suggests that not wanting to burden friends with the hardships with caring for someone waiting for a transplant is something caregivers often experience. Although they wanted to share their experiences with their friends, they struggled with whether or not to do this. This underscores the need for caregivers to have an outlet to share their daily experiences with, one outside of the family unit. As Lawrence highlighted, being a spousal caregiver is something one needs to share with others, yet ambivalence as to whether one should exist.

Getting outside of the home provided much-needed breaks from caregiving and the associated stress for many of the caregivers. For Molly, working at her job in the local community was seen not only as a source of financial comfort, but was also identified as being an imperative coping mechanism. Getting outside of the home gave Molly the opportunity to share her story with strangers; allowing her to feel less alone in her caregiving experience. This sharing of experiences was seen as an emotional release and a coping mechanism, as it helped her to understand there were others going through very similar struggles. This release allowed Molly to return



home at the end of her workdays feeling rejuvenated and able to continue providing care for her husband and family.

*It made me feel good to hear their story and give them my story, and then knowing that there's other people out there than me going through this. Just to get out and mingle and socialize with difference people other than your own family members to me was great. And to get.. It was a release too to get away from all of the sickness and dwelling on.. Like you know, like 5 years dwelling on something everyday.*

Lawrence also shared how helpful it was to speak to his friends and acquaintances about his wife's condition and his role as caregiver. Lawrence described how it was through these conversations and supports outside of the home that he was able to work through the challenges of caring for his wife and the family. He shared that this gave him a renewed perspective that he would not of had otherwise.

*Sometimes its through talking with friends that I guess don't see us often. Just that I can go talk to and bounce thoughts off of.*

Faith emerged as an important concept for some of the caregivers as they coped with living with caring for their ill spouse. For some, this faith included a belief in God, who they felt would ultimately assist them through this time of hardship. Molly described how her believe in God and prayer assisted her through each day spent caregiving and waiting.

*Like every day, first thing in the morning when I wake up, I thank god I'm still here. And I do the same thing when I go to bed. I just thank God for all of the good things that happened today.*

Similar to Molly, Holly also identified her faith as being one of the greatest sources of strength as she cared for her husband. Both caregivers saw their faith as being pivotal to remaining emotionally strong throughout caring for their ill husbands.

*My faith is my strong hold. And so I just put him in God's hands and that's all I can do.*

At times, caregivers questioned the social support in their lives. Although the participants valued the compassion, interest and support they received from those around them; they often questioned this support and the intention behind it. Several of the participants wondered if those around them whole-heartedly cared about their situation, or were merely inquiring to be polite. Lawrence described how although he appreciated the support from his colleagues, he often wondered what their motivation behind this was.

*But at the odd time, they'll ask how things are going? It would be a 3 or 4 minute conversation... And there's also sometimes you wonder are they really listening or do they really care? Or are they just asking to be nice? I don't know, I just think that sometimes.*

The support from friends and family was not only questioned, but also came as a source of stress for some of the caregivers. The caregivers shared how they did not want to be viewed differently in the eyes of those around them and how they did

not want to be regarded as the family waiting for the transplant or the family with liver disease. Caregivers did not want to be pitied, nor did they want to negatively impact the lives of others. The caregivers did not want others to feel sorry for them; they simply desired friendship and social support.

*Well, there is one or two that I can confide in and say anything. But I find it seems like it's a pity trip with them. It's like they feel bad for me. And I don't want that. So like the friend I got in Truro, she's probably the most one I confide in. But when I was leaving, like she had tears in her eyes. She said, "Oh my god, good luck." It's just like, "I feel so bad for you." Like why do I even tell you if you're going to feel bad?*

The caregivers shared how they coped with waiting for a liver transplant. Regardless of how long they had caring for their ill spouse, the participants shared how the many supports in their lives assisted them. These supports included other family members, faith, social events and activities outside of the home. These coping mechanisms were important for caregivers and patients alike, as they waited for a transplant to become available.

#### 6.4.2 In Summary

Waiting for a liver transplant to become available was a tumultuous time for caregivers. This wait was not an easy experience for any of the participants in the study; all identified the need for various levels of support. Caregivers shared how important it was to locate sources of strength to get through the most challenging of days spent caregiving for their spouse awaiting transplant. The caregivers relied on each other, their families, their social networks and their activities outside of the

home to get them through the time spent waiting. The many sources of strength and resiliency identified by caregivers highlight the need for further supports to be offered to caregivers as they cared for their spouse.

## **6.5 Riding The Emotional Roller Coaster Of Waiting**

Being a caregiver of an individual with end stage liver disease awaiting transplant came with it a myriad of emotions, many of which were unique to the caregivers. The caregivers in this study described this time as a rollercoaster; filled with many unpredictable and unexpected ups and downs. Caregivers described the many emotions they experienced throughout this wait, and how these affected their family. These emotions impacted upon the daily lives of these caregivers, and not only changed how they felt mentally and physically, but how they lived their lives.

### **6.5.1 The What Ifs: Thinking The Worst**

Unfortunately, the emotional roller coaster that individuals providing care for their spouse waiting for liver transplant found themselves on meant experiencing emotionally difficult lows and highs. The participants shared that the darkest, most challenging of days were often a result of their own emotions and thoughts. Although all of the caregivers remained hopeful that their spouse would receive a transplant and their lives would return to normal, there was always the possibility that they would not receive a transplant, or that it would not be successful. Both patients and caregivers shared how despite their best efforts not to think about the worst case scenario, these thoughts often flooded their minds. Rumination on the negative thoughts had the power to change the mood for the entire day for the caregivers. Lawrence shared that the possibility of the worst-case scenario came from the

uncertainty of what might happen with his wife's condition prior to receiving the transplant. Uncertainty often took over Lawrence's thought processes, making it difficult to remain positive at times. Caregivers had to learn to negotiate and accept living with the unknown; not an easy task.

*You just kind of get bogged down in thinking about.. Your mind goes to the worst case even though I think we're in good hands. There's also a lot of unknown. And who knows really what's going to happen. So I think it kind of takes over in my mind.*

When these worst-case scenario thoughts invaded their minds, many caregivers shared their coping mechanism of thinking of better times. This coping mechanism helped Molly through these times of hardship, helping her continue on as her husband's caregiver. Both Molly and Lawrence found this coping style to be effective in getting them through their most troubling and depressive emotions.

*When you're stressed... When you're depressed, it's because you let your mind do it for you. Right? And you have to start thinking positive. Like sometimes I think about a bad thought. I take that out of my mind right quick. Like sometimes... Don't get me wrong, sometimes I think about the surgery – my god, what if something happens in the surgery, right. And then I get this scary feeling in my body. But then I totally... When I get a feeling, I totally switch the thought around and think about, like, a happy day. Like the day we got married.*

Avoiding the negative thoughts of the worst-case scenario was challenging, given that many aspects of the life for both patients and caregivers were influenced by

the wait for transplant. Holly shared how much of her life was influenced by her husband's disease and the need for her to provide constant care for him. This need made it difficult to avoid the intrusion of negative thoughts. The insidious nature of waiting was present in many of the activities patients and caregivers did. The inability to escape waiting, even for a short period of time was emotionally exhausting, draining and overwhelming for the caregivers.

All but three of the participants were over sixty-five years of age and retired with children living outside of the home. Two out of four of the caregiver participants were all of working age with children still living in the home. Although one of these caregivers appeared to be at peace with the uncertain future, others acknowledged that this uncertain future could mean several different things. If the most tragic events occurred, Lawrence identified that this could mean a future without his wife, mother of his children.

*When I'm talking about it, was that our last Christmas as a family? Was that our last vacation as a family? And what if things don't happen the way we want to? And what happens with us? the survivors, the kids, and the extended family? What happens after that? Those are conversations that have to happen but it just seems whether or not we're avoiding it or just not believing that that's going to be necessary, kind of thing.*

Lawrence spoke to the constant worry he felt with each passing holiday, celebration and vacation. Lawrence described his constant worry and question of whether that would be the last they experienced a whole family – with their cherished wife and mother. Although throughout his interview Lawrence identified a sense of

hope for his wife's health, he also shared his fears about the future of her health. A sense of loss is illuminated throughout Lawrence's interview, as it appears he feels he and his children would be lost without their wife and mother. Lawrence questioned what their life would be like without her and what they would do. It would be reasonable to assume that Lawrence's life has been so focused on his wife and caring for her, that it is difficult for him to imagine a life where he is not caring for her.

*And once that does happen then we can figure out what the future really is. But sometimes I think of it as what are the kids and I going to do, and what can I do... My son is year from graduating high school and going off to university. And I think of that today sometimes as how am I going to deal with that, not how are we going to deal with that? I sometimes may think what am I going to do by myself with the kids? Can I handle the house? Can I handle the kids' obligations? Can I be everywhere at once?*

For Lawrence, the death of his spouse would leave him picking up the pieces left behind by the loss of his wife, and his children's mother. For all of the caregivers, the loss of their spouse would mean a significant change in their lives, given caring for their ill spouse now took up the largest part of their days. The lack of discussion directly speaking to what life might be like if their spouse was to pass away from their liver disease may be attributed to the fact that imagining and/or speaking about death was simply too painful for the caregivers. It appeared as if talking about death brought this possibility too much to the foreground for the participants, which was simply too emotionally difficult to contemplate.

Being a caregiver not only meant protecting the spouse, but also the children. Lawrence described the importance of protecting the children from the harsh reality of their mother's disease, while spending as much time as possible together. The wait for liver transplant threatened the family's future, and encouraged them to spend as much time together as a unit as they could. It threatened the family milestones such as graduations, birthdays and holidays, which made each passing event challenging for the entire family.

*We don't put it in the context, you know, "Hey, kids, let's do this tonight because maybe it's the last time". We certainly don't want to turn it into an exercise to get the kids scared to death. It's just something the adults will worry about. But just, making sure that the kids put in the effort to be part of it. And I guess because of that we have more family time. It just feels better. It makes us feel like we're achieving in a sense our purpose as parents. Encouraging our kids to be kids and not worry about the adult stuff.*

Parents of young children facing liver disease and the wait for transplant attempted to balance the need to enjoy the present with the reality of their parent's health. Parents saw the worry of the future as being their responsibility, and that it was their role to ensure their children did not carry the worry of their parents liver disease and need for transplant.

#### 6.5.2 Transplantation; A Source Of Life And Loss

Although the participants were all wishing for a liver transplant to become available, for many this was a source of moral distress. The participants knew that in



order for their family member to receive a liver, another family had to experience a significant loss.

While the concept of another person having to pass away for their family to benefit was distressing for all, some rationalized the idea. Caregivers shared how they themselves were organ donors, and that if they or their family members found themselves in a tragic position where one could be an organ donor, they would. In the example below, Luke shared that although this concept of another dying for his wife's benefit was difficult to think of, it also served as reason for him to become an organ donor himself. This appeared to be a reciprocal agreement, whereby he felt that if another would donate their organs for his wife's benefit, then he too should do this given the chance. Knowing that he would donate his own organs, appeared to bring peace and acceptance to Luke when thinking about his wife's own need for a liver.

*But I understand that, you've got to wait for somebody to pass away before something like that happens. It's a hard thing to think about that somebody's got to die so you can live. But I guess that's why we signed our donor cards. Like I signed my license for my donor card and stuff. When I go in the hospital, it's all on that as a donor.*

Becoming an organ donor himself or herself appeared to be a way in coping with the harsh reality of knowing another must die for their spouse. Being an donor himself or herself appeared to help justify what ordinarily may feel unethical. The participants who discussed the donor and being donors themselves all displayed altruism, as they wished to give of themselves without receiving a direct reward. This altruistic behavior is a paradox for the caregivers, as they themselves are deciding to

donate their organs, yet unless they end up with end-stage organ failure, would be doing so without any direct benefits for themselves.

*They're no good to me. Once you're dead, your life is over. So if it helps somebody else to better theirs. I said that there makes...to give somebody else my organs, and they could get 21 years instead of 10 days, I think it's a wonderful thing that they can do that.*

For recipients and their families, immense grief surrounds the fact that the donor was in the position to no longer need their organs; a state of complete brain death. This is not a natural state, and not one that any family ever expect to find themselves in. Recipient families recognized the intense pain that donor families find themselves with, and how arduous it would be to be in the situation to have to suddenly decide the fate of a deceased family members organs. Caregivers shared attempting to put themselves in the position of the donor family and the many emotions they would be experiencing. It was through putting themselves in these shoes that the recipient and the recipient families felt grief, but also felt comfort.

It was not only knowing that the donor no longer needed their organs that distressed the participants, but also how this occurred. The participants spoke of mourning and grieving the loss of the donor, but also attempted to view this in a positive light in order to cope with this grief. Through their grief and distress, caregivers saw the ability for the donor family to be able to extend the caring legacy of the donor, which provided a source of relief for them. It was through reassuring themselves that they were helping the donor and the family with living on the legacy of the donor that helped them cope with knowing the tragedy and sorrow that this

family was experiencing. Although this did not change the fact that the donor no longer needed their organs due to a sudden event or illness, it did help the caregivers to accept this reality and come to terms with it.

The patients and caregivers in this study all described the process in which a new liver would become available. The participants were well aware that unlike in other areas of Canada and the world, the only way in their spouse would receive a liver transplant was through cadaveric organ donation after brain death. Caregivers in this study saw this act of kindness (donation) as thoughtful and meaningful, given that this would give their spouse an opportunity at health, and the chance for a higher quality of life. For Lawrence, the act of someone or their family donating an organ was equated to giving a gift. Although Lawrence was the only participant who specifically used the word “gift” to describe the act of someone donating an organ to another, other participants alluded to the fact that individuals and their families did not have to do this difficult, life-saving act at the end of the life.

*..It's a gift, I guess you could say.*

Organ donation came with the opportunity for the donor and their family to have an ever-lasting legacy by giving ‘the gift of life’. This meant that even beyond the death of the donor, that there would be a lasting gift; a liver that would continue to keep giving for the recipient and their family. The legacy of the donor was recognized and appreciated by the caregiver as they navigated through the thought of their spouse accepting an organ donation from another.

As Lawrence described above, for him, this legacy extended from the often tragic, difficult decision of a family losing a loved one. Molly also saw receiving a

transplant as helping to live on the legacy of the deceased donor. For both Molly and Lawrence, their family would not only be taking from the donor, but would also help to extend the legacy of that donor through caring for their spouse and the donated liver.

*And then that family is very grateful that their son or daughter saved a person's life, and there here you are to live that legacy on for them.*

Although the participants would never know the identify of their spouses donor, or under what circumstances the individual became a donor, it was important to be a 'good recipient' and family. It was not seen as acceptable to take and enjoy the gift – the recipient and family also had to be deserving, appreciative recipients who would not let this precious gift go to waste. Lawrence described that they would do their best to make this gift last, for not only his wife's health, but also for the donor and their family. This would give a continued sense of honor to the deceased donor and their family, as although they would not know it – the liver would be sincerely cared for in order to give another a longer, more fulfilling life. Honoring the legacy of the donor and the person that they were was important to many of the caregivers in this study. Through living a long, healthy life that was enabled by this one person's altruistic donation, the participants saw themselves as able to honor the donor, their family and ultimately their legacy. Carrying on the donor's legacy was essential to accepting the donation, as it was only through this that many of the participants saw themselves as able to comprehend the loss of another that benefited themselves. Participants saw receiving this transplant as not only the gift of life that they had been waiting for, but also an opportunity to ensure this gift and legacy was not wasted.

Patients and caregivers waiting for a liver transplant all thought about where their much-needed organ would come from. The participants described how knowing that something tragic must happen to another family in order for them to receive the liver they had been waiting for was a difficult reality, which many chose to think as little as possible about. This reality leaves recipients and their families feeling morally and ethically distressed; they are ultimately waiting and wishing for a liver, which can only come through the death of another. The concept of the donated liver being a gift from the donor and family, and this gift allowing the donor and family to have a lasting legacy emerged throughout the participant narratives, which shed light on how the caregivers and their families would ensure this lasting donor legacy would be a positive one.

### 6.5.3 Fear And Worry: No Escape

None of the caregivers in this study were born caregivers, thus grew and learned to become a caregiver for their spouse. This caregiving role brought with it not only physically demanding tasks and limitations, but emotionally draining and challenging tasks too. The complexity of caring for someone who was awaiting transplant also gave way to a constant fear and worry of the individual. Fear and worry that something was going to happen to the ill spouse was only experienced by the caregiver. Caregivers in the study, frequently found their thoughts consumed and negatively clouded (by what?) resulting in feeling overwhelmed.

Many of the caregivers shared how regardless of what they did, the constant worry and fear of how their spouse was doing, was with them. The caregivers felt that this worry and fear was a part of their caregiving responsibility, given that they were

the primary caregiver for their spouse. There appeared to be an expectation that they would take on all aspects of care, including the fear and worry that came with it. This is likely a societal expectation, where spouses feel as though they are expected to care for their spouse, in sickness and in health, as stated by the traditional marital vows – ‘in sickness and in health’. The caregivers felt as though everything related to caring for the spouse was their responsibility, and that it was their job to ensure the health of the spouse. They accepted this responsibility, despite the great challenges that came with it mentally and psychologically. This was a constant challenge for many of the caregivers; for some this worry was enough for them to limit their activities and time spent away from the spouse and the home. Although they had a desire to limit this worry, it often overwhelmed them.

*I think, you know, the fear is kind of always in the back of my mind. Every time if I'm away from home for a period of time and I try to call home and there's no answer. I'm expecting my wife is at home, is there something wrong? Maybe she's asleep and she didn't hear the phone. But it makes me wonder is that happening when I'm not there.*

Like Lawrence, Molly described that on days where she felt her husband was not well, she would cancel her planned activities and stay home. Molly shared that it did not matter what she had planned, if she felt she was needed she was willing to stay home in order to care for her husband. This was not only about caring for the spouse and feeling they were needed, but also knowing that they would not enjoy themselves if they were gone. Many of the caregivers felt as though it was a lose-lose

situation to leave their spouse alone, even when there were things they had to do outside of the home.

*If I think he's ill, I just won't go. Like you know, I've got to make sure everything... To me, everything's got to be like okay, you had a good day today, I think you're going to be fine. It's okay for me to leave for a couple of hours, right. But if I think... Like if he had a bad day and he was in bed most of the day, I won't bother going because I'll know I wouldn't enjoy myself because I'll just worry about him, right, at home.*

This was a challenge for Lawrence; he was now the only breadwinner for the family and thus had to work. He knew that he had to work and that there were other important activities that had to happen outside of the home, such as the children's schooling and activities, however knowing this did not make leaving his wife any easier.

*But when I see [wife] in those situations, in pain day-to-day, I just wonder... When I see that, I don't want to leave the house that day. But I have to because things happen. There's other things that has to happen.*

For many caregivers, this worry was not without experience. Lawrence had been present during a critical acute episode that his wife had previously experienced due to her liver disease. This past event haunted Lawrence as he described below, and he recalled it each and every time his wife did not respond to his telephone calls. The possibility that his wife could be alone, unconscious and unresponsive; as she had been that one time was enough for Lawrence to live with a constant worry and fear that it may happen again. The worry was that this time he

would not be there to help. This past event in their lives made Lawrence question what he could do in the event that it occurred again. Lawrence felt a duty to care for his wife and to protect her, and struggled with the idea that there was nothing he could do to prevent such an episode from happening again. He had to learn to live with the idea that this could happen again if his wife did not receive her much needed liver transplant. Not being able to ensure his wife's safety and welfare was distressing for Lawrence, as he was willing to do whatever it took to help his wife.

*It's very frightening and upsetting and scary. And you know, knowing that the liver is kind of in poor condition, there is a likelihood that that could happen again. And you know, how can I know before it happens?*

The caregivers felt as though it was their duty to ensure the ill spouse was adequately cared for, and that they did not go without anything they needed or wanted. Although only Molly specifically spoke of feelings of guilt, guilt came through in several of the caregiver narratives, especially when the caregivers spoke about partaking in activities outside of the home. These feelings of guilt also appeared to stem from caregivers having the physical ability to do things that the ill spouse was no longer able to do.

*And like I always have that worry. Like you know, should I go home? Or it's either worry or guilt. I don't know what it is. But I'm constantly worried about him, right. Like should I be home with him? Maybe he's not feeling well. Maybe he can't make himself a snack or... Like you know, it's always playing in your mind, right. Like right now I'm worried about him because he couldn't come because he wasn't feeling the best. He was getting a headache. And I*



*said, well, maybe you should go back and lie down. And I told him, don't worry, I'll be back before the hour is up. You see? You know what I mean? Just I'm just worried if he's okay there by himself, right. I don't know if it's a guilt thing or a worry thing, right. Like I feel guilty because he can't do it, right.*

This worry was not only present during acute moments when the caregivers were unable to contact their spouse, but was also present in their everyday thoughts. For Holly, this worry surrounded her husband's encephalopathy that he had developed as a result of his liver disease. Holly did not share the same worries as the other caregivers; her worry was that he would not recover from one of his encephalopathy episodes and would sustain permanent brain damage. Given her husband's health and condition, this was worry was a reality for Holly, as she saw the gradual increase in encephalopathy episodes in her husband.

*And I mean I just know I do read on it and I know that the encephalopathy is very dangerous. So that's a concern that he's, you know, going to go into one of these states and he's going to have brain damage, and not come back to himself again.*

Caring for a spouse that was awaiting liver transplant was emotionally, psychologically, physically and mentally arduous for the participants in this study. The caregivers lived with a constant fear and worry that their spouses condition would worsen, which limited their daily activities outside of the home. The caregivers were challenged by these emotions, as they attempted to carry on regular behaviours such as work, visiting friends and family and looking after the family affairs. Despite

their best efforts, the caregivers described how invading these fears and worries were and how many of these worries intensified as the days, weeks and months past that their spouse remained waiting.

#### 6.5.4 Self-Care: An Afterthought

Caregivers experienced caring for themselves both mentally and physically very differently from the patient participants. Caregivers spoke of the many caretaking activities and roles they fulfilled both inside and outside of the home. They spoke of the many things they now found themselves having to do, and the countless hours spent providing care for their ailing spouse and the family. For the caregivers in this study, caring for themselves both physically and emotionally came as an afterthought. The caregivers saw fulfilling the needs and wants of the family and ailing spouse as being more important than their own. It was only when asked how they cared for themselves did the caregivers speak of the things they did for themselves. It was rare that the caregivers took time off from their full-time role of caregiving in order to care for themselves, let alone consider their own needs in the run of a day, as Lawrence highlighted below.

*I am kind of the one that worries about making sure every day else is okay. So I do what I can for my wife and make sure the kids are off to their activities and are in a good place. And if there's time left then deal with myself. I guess in a lot of ways I'm an afterthought in my own mind.*

Lawrence looked after the many needs of his family without considering his own needs. Knowing his family and wife were well looked after mentally, physically, emotionally and financially took precedence for Lawrence, even when it meant

compromising his own needs. On the surface, Lawrence acted as if this did not bother him, however it became evident throughout the interview that Lawrence knew this lack of attention to himself meant he was not coping well with his wife's disease and wait for transplant.

Lawrence was challenged with balancing attempting to care for himself, his work and the needs of his wife and young children. He was challenged with the balancing act that his wife's liver disease and wait for transplant brought to his life. It was in the most challenging of moments where his perceived lack of coping became magnified to him. Maintaining the façade that he was successfully balancing all aspects of his wife's care and their life was critical for Lawrence. He felt as though he needed to provide this care, regardless of how difficult it was for him. In providing all of the care, it appeared as though Lawrence would not experience any adverse effects, i.e: feeling as though he had failed. For Lawrence, it was too difficult to ask for help, when it was he who helped everyone else. Being the caregiver for everyone meant feeling as though he had to be the strong one, not the one seeking help from others.

Although not discussed by Lawrence, there are tolls associated with compartmentalizing one's feelings and emotions. Not addressing these emotions can lead to a buildup of extreme emotion, anger and sadness, which has implications for not only the caregiver but the patient and the entire family. The compartmentalizing of these emotions can contribute to caregiver burnout, which highlights the need for caregivers to be able to identify and work through these emotions.

Learning to balance it all as a caregiver was not something that came easy for any of the caregivers. The caregivers described how caring for themselves often came

last on the long list of responsibilities and duties they had. For some, it was easier to compartmentalize their feelings and emotions rather than express them, as many did not want to upset their ill spouse or families. However, learning to express their emotions was an effective coping mechanism for many of the caregivers in the study, as it was through this expression they felt a sense of comfort and relief.

#### 6.5.5 In Summary

The caregivers found themselves not only with the role of coping with their own emotions but also those of their spouse and the entire family unit. This burden of emotional caregiving falls upon the caregiver, which often leaves them little time to take care of their own emotional health and well-being. Many caregivers feel as though it is their job to protect their spouse and often feel alone in caring for themselves. For the caregivers in this study, not letting their mind wander to the many negative possibilities for their spouse's health; the 'what ifs' was challenging, however a sense of hope and optimism appeared to help them through these darkest moments in their lives.

## Chapter 7 Discussion

### 7.1 Introduction

This phenomenological research study explored the lived experience of patients and caregivers in Atlantic Canada waiting for a liver transplant. The review of the literature and this study highlighted the importance of understanding how patients and caregivers experience waiting for a liver transplant. An interpretive phenomenological approach was employed in this study, given the scant research on this topic in the extant literature. In our understanding of how and in what way patients and their caregivers experience waiting for a liver transplant, there is a significant gap on the experiential nature of waiting in general. Much of the focus has centered on wait times – a more tangible aspect of the wait experience that can be quantified. Although beneficial in determining the average time spent waiting for transplant etc., quantitative approaches leave out the contextual nature of the patient and caregiver experience. Perhaps, more importantly, caregivers have been largely left out of the research on how and in what way, waiting affects their day to day life, particularly as a caregiver within the context of liver transplantation serving as further justification to conduct this study.

The theoretical frameworks; the family resiliency framework (Walsh, 2003) and the uncertainty in illness theory (Mishel, 1981) helped to inform my thought processes and provide a lens for both my analysis and interpretation of the participants experiences. Patients do not experience their illness or wait for transplant in isolation; the experience is shared amongst their spouses, children and families. Families and caregivers of these individuals waiting for transplant cannot help but

experience the wait; it encompasses their lives. To strengthen my interpretation and analysis, Walsh's family resiliency framework provided a lens in which I could interpret how families come together in the face of adversity to overcome the arduous time spent waiting for transplant. This framework guided my thinking and understanding in how a family's ecological perspective and developmental stage impacts their ability to be resilient. This was especially important given the diverse developmental stages of my participants; several had young children and worked, while others were retired with grown children. The uncertainty in illness theory assisted me in understanding the turmoil that waiting for a transplant brought to the lives of the patients and caregivers in my study. Mishel's theory guided my understanding in how the uncertain nature of awaiting transplantation impacts upon the lives of those waiting, and how this uncertainty can change their lives. Although these theories were chosen prior to data collection and analysis, both were relevant to the study findings. In particular, the family resiliency framework proved to be extremely relevant to my findings, given that each of the participants spoke of waiting for a transplant as a family affair; one in which no member could escape. Rooted within the experience of waiting for a liver transplant for both patient and caregiver was the notion of resiliency, and coming together as one family unit to overcome the adversity that end stage liver disease and waiting brought to their lives. All of the participants also spoke of the uncertainty that came with waiting and being on the transplant waitlist.

Mishel's uncertainty in illness theory was also relevant to my findings and helped me to further understand how different individuals conceptualize their illness,

and the factors that mediate their ability to conceptualize and assign meaning to their or their spouse's illness. Mishel's theory guided me toward understanding how the participants conceptualized their illness; assisting me to understand the factors that allowed some individuals to be at peace with the uncertainty waiting brought to their lives, and how this same uncertainty brought turmoil and disruption to the lives of others. Furthermore, the *Uncertainty in Illness* theory proved to be most relevant in understanding how we, as health care providers, can help individuals to find meaning in their illness, which ultimately facilitates a more positive conceptualization of the inevitable uncertainty they find themselves faced with. Taken together, both theoretical frameworks added clarity to and greater understanding of the phenomenon of waiting.

Using an interpretive phenomenological approach allowed a rich description to emerge of how patients and caregivers experience the wait for a liver transplant. While common themes were shared across both patient and caregiver experiences, there were also many differences. At the heart of the wait for transplantation, both patients and caregivers found themselves in a *conundrum of hope*. They were hopeful that a liver transplant would become available, but knew of the barriers. In this chapter, I will outline my thoughts and interpretations of the findings from my perspective as a nurse and phenomenological researcher. I will discuss how the findings from the patient and caregiver perspective reflect and/or contrast with our current knowledge and understanding of liver transplantation. Four core themes emerged: Waiting for the Phone Call, Light at the End of the Tunnel, Riding the Emotional Roller Coaster of Waiting and Negotiating the Disruption: Redefining

Self, all of which fall within the overarching theme of the *Conundrum of Hope*.

I noted there to be a considerable amount of similarities between how patients and caregivers described their experience of waiting. These similarities were primarily around the experience of waiting for the phone call, the roller coaster of emotions experienced as a result of waiting, the need for coping mechanisms, sources of strength and for negotiating the disruption to their life. In contrast; there were also many differences between the patients and caregivers. Predominantly, these differences existed between the changes to the everyday lives of the patients and caregivers, how caregivers looked after themselves while waiting and the fear and worry caregivers experienced. The following discussion will review the findings of this study and my interpretation, while remaining true to the voices of those who participated.

## **7.2 Conundrum Of Hope**

The patients and caregivers in this study had to learn to accept that in being listed for liver transplant, there would be a wait impacting on their everyday lives. In asking the simple question to these two groups individually, “What is your experience of waiting for a liver transplant?” patients and caregivers opened up to me on what it is like to wait for a liver. In sharing their experiences, four themes emerged that helped to define the experience of waiting for a liver transplant for both patients and caregivers.

- Waiting for the Phone Call
- Light at the End of the Tunnel
- Riding the Emotional Roller Coaster of Waiting



- Negotiating the Disruption: Redefining Self

Within each of these four themes, present for both patients and caregivers in this study, I noticed there to be one consistent thread or overarching theme. Present in each of their experiences they shared with me, was a sense of hope, which permeated their daily experiences and thoughts regardless of whether the day was filled with negativity or optimism. It was reflected in their stories of personal dreams, goals and desires for the future or when they spoke of their uncertainties and fears. Its presence existed within all of their daily experiences and how they regarded life and the life ahead for both themselves, their spouses and their families.

In sharing their stories with me and through my interpretation of these stories, I came to refer to this phenomenon as the *conundrum of hope*. Patients and caregivers shared the belief that regardless of the hardship, emotional turmoil and tumultuous wait they were experiencing for transplant, that a transplant would come, and that a happier, healthier and positive future would follow. To remain hopeful, meant believing that a suitable transplant would come in time, and that it would be successful for many years to come.

The Oxford Dictionary (2014) defines hope as being a feeling of expectation and desire for a particular thing to happen. All seven participants, four caregivers and three patients, remained hopeful they would have a positive outcome. This hope was unwavering; it was present during the most arduous of times and the most uncertain of days. Conundrum is defined as being a confusing or difficult problem or question (Oxford Dictionary, 2014). Together, a conundrum of hope came to reflect moments of difficulty and confusing interlaced with a desire and expectation for a positive

outcome, the transplant and regained health. Existing within the *conundrum of hope* afforded a buffer from the reality of waiting, a brief respite and space to breathe before continuing on with their daily lives.

For the participants, being hopeful meant believing that despite the odds, risks and potential outcomes better days would come. Hope is considered a universal human phenomenon, as crucial to overcoming hardship and remaining resilient (Ong, 2006). It was not about unrealistic or false hope that a transplant would occur and all would be magically better; rather, it was about knowing the risks and balancing the reality that things may or may not work out.

While examining hope within the extant literature, I found the need to differentiate between hope and optimism, which are at times, was used interchangeably. Snyder (1991) defined hope as the motivation to attach oneself to positive outcomes or goals. He distinguished between hope and optimism, stating that hope is an emotion that involves a reciprocal action between efficacy experiences; in contrast, optimism is viewed as a focus on outcome expectancies. Similarly, Averill et al. (1990) stated that people hope for things that are important to them, even if there is a low probability of the outcome occurring. In my interpretation of the participants in this study, I found hope and optimism to differ in that individuals were only optimistic when the likelihood of the positive outcome occurring was high. Hope existed independently of optimism, distinguishing the two from one another. Although linked and often co-existing, optimism and hope are conceptually different (Helland & Winston, 2005). It appeared as though the participants experienced the emotion of optimism, while remaining hopeful that their desired outcome of

transplantation would occur. Despite this, hope for caregivers and patients in my study were filled with uncertainty; there was no guarantee of what the future would bring. Although I found the participants to be both hopeful and optimistic, I interpreted their experience as being primarily hopeful, given that they understood the possibility that outcome negative outcome was equally realistic (i.e: successful transplant). This is consistent with the literature that shares that hope is the anticipation of achieving a personally good future (Dufault & Martocchio, 1985), potentially possible not necessarily probable (Cutliffe & Herth, 2002).

Patients and caregivers in this study remained hopeful, and at times optimistic about the future. It has been found that optimism and hope have been associated with a decrease in physical symptoms for both acute and chronic illness (Beckham, Rice, Talton, Helms & Young, 1994, Reed, Kemeny, Taylor & Visscher, 1999, Fournier, de Ridder & Bensing, 2002, Glazer, Emery, Frid, Banyasz, 2002). Furthermore, a large meta-study of 83 studies of patients with various physical and mental health ailments by Rasmussen, Scheier & Greenhouse (2009) found optimism to be strongly correlated with physical health outcomes. The above literature supports the positive impact that optimism can have on patients and families experiencing illness or disease. For the participants in my study, this could mean that their optimism and hope was not only benefitting their mental and emotional health as reported, but also their physical health. In particular, research examining the effect of optimism on transplant patients, found that those who have a good sense of coherence and an optimistic attitude before transplantation will experience positive mental health post-transplant (Goetzmann et al., 2007). Similarly, O'Carroll, Couston, Cossar, Masteron

& Hayes (2003) found that pre-transplant neuroticism (i.e: anxiety, depression, worry) predicts a lower quality of life after transplant.

In listening and interpreting what patients and caregivers shared with me, I noted an overarching need to be hopeful. It was as if participants felt compelled to share with me this resounding hope and optimism that they would have a favorable outcome. I found myself asking whether we, as health care providers allow our patients to be anything but optimistic and hopeful. I wondered if, in my own practice as a perioperative registered nurse, I allowed patients the place, space and time to be pessimistic, negative, unsure or uncertain about their prognosis or future. Do we, as health care providers, listen to our patients and families when they are sharing these concerns or feelings of loss with us, or do we refuse to ‘ go there’ with them? In refusing to engage in conversations about challenging concerns such as death and loss, we may be attempting to protect our patients and ourselves as health care professionals. Research by Kennedy Sheldon, Hillaire & Berry (2011) found that although health care professionals acknowledge 57% of socioemotional cues, they only respond to 22% of these. Similarly, work by Uitterhoeve et al. (2007) found that nurses respond to only 32% of patients’ emotional cues. Reasons for this have been cited in the literature by Betcher (2010), finding that nurses and other health care providers may ‘block’ these emotions from patients and families, as a self-defense mechanism to protect themselves from their perceived inability to address these emotions. Furthermore, health care professionals may exhibit this blocking behavior with the fear that conversations about death and end of life concerns will diminish

hope and cause further distress for the patients and their families (Anselm et al. 2005).

Many health care professionals may see it as their role to protect the patient from the truth, possibilities or reality. Not doing so is perceived as a challenge, as health care professionals must maintain the balance between encouraging realistic hope and creating realistic expectations of health outcomes (Leung, Silvius, Pimlott, Dalziel & Drummond, 2009). They grapple with the desire to help patients and families maintain hope, while not promoting a sense of false hope in the context of life limiting illnesses (Scanlon, 1989). For many health care providers, it is easier and safer for all involved to stray away from the ‘hard’ conversations of death and loss. Other reasons for withholding, or not disclosing health information have been identified as a lack of time to attend to patients’ emotional needs, and a fear of a negative impact on the patient (Hancock, Clayton & Parker et al., 2007). As a result, an environment within the health care field has been created where both health care providers and patients have viewed anything less than optimistic and curative as a failure. This is supported by the literature on the curative model of medicine, which suggests that when cure is the ultimate goal of medical providers, death is the ultimate failure (Fox, 1997). Similarly, it has been suggested that physicians worldwide follow the principles of Ambroise Pare’s maxim of ‘always give the patient hope, even when death seems at hand’ (Pare & Packard, 1921). Given that patients and families look to physicians for hope, it is of concern if physicians and other health care providers do not truly listen to the feelings of patients and families. Although it is important for physicians to give and maintain hope for patients, a space

where patients and families can lack hope or feel loss needs to be created and shared. Although my participants did not speak of being forced to be hopeful, this may be something they experience as a result of the climate created by health care providers. They may feel as though they are not able to speak their feelings if they are not optimistic, hopeful or positive, as many spoke of feeling grateful to be placed on the transplant list. In my interpretation of this phenomenon, I wondered if my participants felt because they were on the list they should be happy that they were being given the chance at health and life.

The unwavering hope displayed by the patients and caregivers in my study has potentially life changing implications. For these individuals, hope could mean better physical and mental health outcomes. Although they did have extremely difficult, trying days while waiting for transplant, it appeared that hope was usually within reach. At the end of the day, both caregivers and patients thought that they or their spouse would get the transplant they had been waiting so desperately for, and that their lives would get 'back to normal'. While I am unsure as both a nurse and researcher that their lives will ever be the same after transplant, their hope for this shows their true belief that they would get the transplant, despite how long they had been waiting. In addition to maintaining this hope, it appeared that for both patients and caregivers, it would be difficult to imagine life after transplant and how it may be changed. This fear of how the future might change, even post-transplant left both patients and caregivers clinging to their notion of their 'old normal', or life prior to waiting. Within the *conundrum of hope*, I believe that the patients and caregivers in my study were unknowingly helping each other through the wait; that such an outlook

served as an effective coping mechanism. I found myself asking if liver transplant patients and families were unique in their manifestation of hope, or whether this could be found in patients and caregivers awaiting various transplants. This leaves room for future research to be conducted that examines hope in the context of patients and caregivers awaiting organ transplants.

### **7.3 Waiting For The Phone Call**

In waiting for a suitable liver to become available for transplant, both patients and caregivers revealed how debilitating it was both physically and mentally to wait for the telephone call signaling a liver was available. Patients and caregivers experienced the wait for the phone call similarly. Both described that waiting for a transplant meant waiting for ‘the call’. Caregivers and patients experienced fear, worry, uncertainty and anxiety upon hearing the telephone ring; each ring brought with it the hope that this could be the call for transplant. The importance of such a call meant making themselves accessible at every hour, of every day.

The intense emotions experienced when the phone rang, changed the way in which patients and caregivers lived in their own home. Patients or caregivers could not escape the need to be available 24 hours a day, seven days a week. They experienced time as hours, days, weeks, months and years. Although the participants spoke of this “clock time”, they moved between the notion of clock or linear time versus the lived or embodied contextuality of time. From an embodied perspective, participants were no longer taking spontaneous trips or vacations, no longer going out for day trips fishing or boating. For others, this meant having to use new technologies such as cellular phones, an umbilical cord connecting them with family members

and/or healthcare professionals. For some, this connection served to reinforce an unwelcomed decrease in freedom, whereas for others the connection was a relief; knowing they could be contacted whenever needed. While both patients and caregivers in this study talked about the connection, caregivers faced greater obstacles and restrictions; they needed to remain accessible to their spouse at all times, ensuring that they were never truly alone in their wait.

These findings are consistent with the literature that suggests that patients have to surrender opportunities to travel and visit family and friends not close to the transplant program, leading to the inability to do the things they dreamed of (Brown, Sorrell, McClaren & Creswell, 2006, Moran, Scott & Darbyshire, 2011). It was because of these harsh restrictions and limitations that waiting brought to their lives, that many patients and caregivers felt that waiting for the call was the hardest aspect of the wait for a liver transplant. However, patients and caregivers felt ambivalence about the wait. On the one hand, they could not wait to get the call for transplant; on the other they were fearful and worried about receiving this call. The ambivalent nature of the wait led some participants to question their readiness for change – their lives could be turned upside down - were they ready for the risky surgery and lengthy recovery post-transplant? The waffling and questioning was experienced as an emotional roller coaster.

For these individuals, this constant waiting by the telephone placed lives on hold; a pause button had come into effect. Plans of the future were suspended, leaving patients and caregivers physically and mentally confined. A life placed on hold, lived out in anticipation of a beeper going off, a phone call coming in has been reflected in



the stories of others awaiting organ transplant (MacDonald, 2006, Moran, Scott & Darbyshire, 2010, Williams, 1991, Yelle, Stevens, Lanuza, 2013, Rickman, 2001, Wainwright, 1995, Baker & McWilliam, 2003, Naef & Bournes, 2009).

Participants in this study expressed that over longer periods of time, the intense emotions surrounding the wait for the phone call decreased. They began to normalize the wait for transplant, becoming desensitized to the wait and the impact on their lives. Patients and caregivers waiting for more than six months, no longer remained as transfixed on the telephone; they knew they had to do more than focus on the phone. Research suggests that patients' perceptions of waiting change over time, often with the realization they have to do more with their life than wait by the phone (Ivansson, Eckmehag & Sjoberg, 2012).

The experience of waiting for the phone call included a number of differences for the caregiver from that of the patient. Waiting by the phone was distressing and all-consuming for caregivers. For the caregivers, this meant an alteration in their daily activities, where they could go and what they could and could not do. Caregivers found themselves restricted, yet also had to continue on with their activities of daily living, for many included working outside of the home. This led to feelings of being on hold, similarly described by the patients. Caregivers saw their primary role as caretaking for their spouse, regardless of how this impacted the other important aspects of their lives: friends, family, work and personal interests. These findings are consistent with those found in the literature of caregivers of individuals awaiting organ transplants, that suggest previously taken for granted activities such as vacations, dinners out and visiting relatives were no longer possible (Kurz &

Cavanugh, 2001, Saxe-Braithwaite & Chapman, 1992).

The implications for caregivers awaiting the phone call for transplant did not end with limitations on their activities; they had to put their activities, joys, dreams and freedoms on hold to ensure that this need was met. For caregivers, being the primary caregiver meant it was their job to ensure someone was always home in case the phone rang. Ultimately, this meant they had to be the person on 'guard' for the call. Being in charge of this daunting responsibility of the telephone, left the caregiver physically and mentally exhausted, as they attempted to minimize the negative effects waiting for the phone to ring had on their ill spouse.

Both caregivers and patients appeared to use "buffering", whereby each attempted to protect the other from the emotional hardships associated with waiting for a transplant. Protective buffering has been defined as "hiding one's concerns, denying one's worries, concealing discouraging information and yielding in order to avoid disagreement" (Hagedoorn Buunk, Kuijer, Wobbes & Sanderman, 2000, p.275). While trying to protect their spouse, there was a sense of needing to be strong on the part of the caregivers. Unique to the caregivers, was the idea that they needed to be the "rock" holding it all together. They felt as though they needed to be the resilient figurehead getting the family and spouse through this difficult time. This left caregivers' emotions unaddressed, giving way to the potential for caregiver burnout and caregiver role strain. Studies suggest that protective buffering by caregivers results in negative consequences for the caregivers (Butler, Turner, Kaye, Ruffin & Downey, 2005, Coyne & Smith, 1991, Trost, 2005).

Neither patients or caregivers wanted to negatively impact the other, however

this appeared to leave both individuals feeling hopeless and helpless. In particular, the caregivers in this study took care of everyone else; their ill spouse, the children and for some, their parents. Despite the challenges they experienced being a caregiver, they did not want their ill spouse to feel they had to care for them as the caregiver. The caregivers in this study saw their spouse as having enough to deal with on their own, and did not want to add to their emotional pain and chaos. Unloading on their spouse would mean an increased burden on the spouse, which they wished to avoid at all costs. What became apparent to me was how complex this situation was for the caregivers and their relationship with the spouse. The caregivers knew that internalizing their emotions was unhealthy and that these difficult conversations should be had with their spouse.

Through listening to the patients and caregivers and my interpretation of their stories, it became apparent to me that as a health care system, we are failing at offering the opportunity to learn to effectively communicate with one another during times of illness and hardship. Further research is required to understand the needs of caregivers and patients dealing with the wait for transplant, and how we can help to facilitate the couple's ability to have open communication.

#### **7.4 Negotiating The Disruption: Redefining Self**

For patients and caregivers awaiting liver transplant, the experience of waiting was centered on the changes they were forced to make to their everyday lives. Life as they had once known it was no longer. Patients, caregivers and their families had to adapt to the differences that end stage liver disease and being placed on a transplant wait list required. Patients not only had to come to terms with the undesirable changes

brought to their lives as a result of their liver disease and wait for transplant, but also had to accept the changes that it brought to others. For patients, this meant knowing their liver disease was negatively impacting all of those in their lives, especially their spousal caregiver and immediate family members. For both patients and caregivers, this ultimately meant learning to negotiate the disruption that awaiting transplant brought to their life.

Although there were many similarities experienced by both patients and caregivers in the changes to their everyday, there were also many differences. Caregivers now found their everyday lives filled with new roles and responsibilities. These changes were specific to the caregivers, they meant learning things they had never imagined they would have to do, such as providing hands on nursing and medical care and caring for all aspects of the home. They had to learn to define who they were, and the way in which they viewed themselves. Many of these new tasks presented as a challenge for the caregivers, as they now found themselves without a choice; if they did not take on the needed tasks, they would not be done. Despite the challenges and inner resistance, caregivers did their best to accept the new roles; in doing so they were ultimately caring for their ill spouse and family.

Caregivers in particular may have been hesitant to share their feelings about how the relationship with their spouse had changed; for fear that this would sound as if they begrudged caring for the spouse. They may have felt I, as a nurse would judge them, if they had shared feeling as though their relationship had changed as a result of caregiving. Research literature highlights how spousal caregiving leads to a disruption in the relationship; however, when asked, the caregivers in this study

indicated that they did not feel the relationship with their spouse had changed. Furthermore, they did not feel their role as husband / wife was threatened or changed by the need to be a caregiver. Although they said their relationship had not changed, it became apparent to me that the relationship was different. Many of the caregivers found themselves in a supervisory, advocacy role over the patient; ensuring they took their medications, attended their appointments and ate the required diet. Caregivers struggled with giving the spouse independence while ensuring their health. This change in relationship mirrors a parent-child relationship, where one has power and supervision over the other. The shifting relationship between spouse and caregiver was most profound for those with advanced liver disease affecting not only the body, but also the mind. This disconnect between what the participants shared, and what was observed may be due to the societal and moral expectation that spouses; particularly females should care for their spouse (Eisdorfer, 1991, Halm, Treat-Jacobson, Lindquist & Savik, 2007, Armstrong & Armstrong, 2004).

As the research suggests, it is important to highlight that unlike other relationships, the couple relationship is unique (Greenberg, Stacy & Penzo, 2002), where “they negotiate new relationships as a twosome with many other subsystems” (McGoldrick, 1998, p. 231). As Greenberg, Stacy & Penzo (2002) share, although couples care for each other throughout their lives together, this relationship is altered when one member of the couple becomes ill. When facing illness, couples must learn to maintain a mutually balance relationship, while one becomes patient and the other caretaker (Rolland, 1994). Studies suggest that couples facing illness must contend with the uncertainties in planning their lives and achieving goals that are now

threatened (Rolland, 1994). Alternatively, there may be positive impacts as a result of the wait for transplant. Buse and Pieper (1990) found that couples awaiting heart transplantation experienced an increased closeness and tenderness. This highlights the need for further psychological services for caregivers and patients, while they negotiate the changes to their relationship.

For caregivers in this study, being a loving, supportive spouse meant doing all they could to provide the necessary care. In my interpretation, I found myself pondering where this sense of duty to provide care came from. I found myself asking if this expectation stemmed from the traditional marriage vows, stating that individuals vow to care and love one another “in sickness and in health”. In my interpretation of what the patients and caregivers were sharing with me, I noted that through all of the changes to the everyday and their lives; caregivers and patients were hopeful that their lives would return to ‘normal’, that these changes would be temporary. Alternatively, other research literature has indicated that for some patients and families, a return to life as it was pre-transplant is viewed as impossible (Mendes & Bouso, 2009, Chou, Chen, Chen, Chen & Mu, 2008).

The caregivers shared they felt they could be both a spouse and a caregiver, despite the changes that caring for their ill spouse brought. They saw spousal caregiving as a duty; something they were going to do regardless of the costs. This is consistent with the literature that found the caregiver moral obligation ultimately trumps all other obligations (Kittay, 1995). Caregivers appeared to feel this duty in a personal and societal sense, but also in a moral sense. Joan Tronto (1993) found that caring has been confined to the moral domain. Furthermore, Tronto identified there to

be moral boundaries that privatize care. Tronto shared how “privileged irresponsibility”; the way in which the division of labour and existing social values allows some to excuse themselves from basic caring work, as they see themselves with more important obligations. This leaves some members of society feeling as though they are entitled to receive caring work from others, without ever contributing this. Moreover, Tronto found there to be four sub-elements within care as a moral obligation. These are attentiveness; suspending ones personal needs in order to recognize and be attentive to others, responsibility; the willingness to take care of the needs of another, competence; having the skill to care for another and responsiveness; considering the position of those they are caring for (Tronto, 1993, Sander-Staudt, 2014). It was evident that the caregivers in my study felt morally obligated to care for their spouse; that they did all that they could to ensure this care as adequate. This moral obligation to provide care may be an unreasonable expectation for some; providing this care adds to the many responsibilities these caregivers already had in their everyday lives, often leaving caregivers feeling overextended. As described in the literature by Tronto, the caregivers in my study were attentive to their spouse and suspended their own needs, were willing to care for their spouse, learned the required skills to care for the spouse and considered the situation of their spouse.

In my interpretation and examination of the aforementioned literature, I questioned whether we, as health care providers allow spouses to remain spouses, as opposed to caregivers. Do we give spouses the opportunity not to be the primary caregiver for their spouse, even though the majority of patients listed for liver transplant remain at home? I asked myself whether or not we push or inevitably

coerce spouses to provide nursing and medical care, even if they consider themselves not to be comfortable and fully competent. As found in the work by Kittay (1995), caregiving work by informal caregivers often trumps all other obligations. These spousal / family caregivers may see there as being no other choice but to care for their family members, despite the cost it has on their life. This is an important distinction to make if we are to improve the lives of spousal caregivers; for these caregivers, caregiving was not seen as an optional task.

The differences experienced by the patients revolved around their disease and how the wait for transplant had impacted their everyday life. Waiting for transplant challenged the identities of patients; they found themselves unable to do the things they wanted. For one patient, this meant no longer being able to work, which had given her great satisfaction, and contributed to her sense of purpose and self-worth. No longer being able to work and contribute to the family financially, was a difficult pill for her to swallow; she now found herself alone and feeling lonely during the days at home. Brown et al. (2006) found the inability to continue working leads to an erosion of self-worth, boredom and a loss of personal identity. Other researchers found that for patients awaiting transplant, letting go of their physical abilities and accepting the need for rest was one of the most difficult aspects of waiting (Brown et al., 2006, Bjork & Naden, 2008, Wainwright, 1995, Diaz-Dominguez, Perez-Bernal, San-Gregorio, Martin-Rodriguez, 2006).

End stage liver disease and waiting for transplant limited the physical, emotional and mental abilities of the patients. They found themselves caught between the life they had once lived and wanted to return to, and their declining health, as they



waited the indeterminable amount of time for their transplant. While they attempted to maintain as much independence as possible, patients found themselves with the inability to keep up with their daily lives and activities. Once considered simple, taken-for-granted tasks such as laundry, now seemed impossible for the patients, as they found themselves exhausted and fatigued. For the patients who had enjoyed physical activity, it was very difficult to accept that they could no longer do these activities. The inability to do physical activities inside or outside of the home meant the patients spent a considerable amount of their day in bed, despite their desire to be active. For many patients, this resulted in feeling depressed, inadequate and as though their entire life was on hold and restricted. They had to learn to preserve their energy by learning their limitations, which presented as a challenge. For patients, this meant feeling less like themselves, as they were not able to do the things they felt were a part of their identity (e.g: work, physical activities, interests).

The significant loss of self was challenging for the patients to negotiate and accept. They desperately wished for their transplant, and for their life to return to 'normal', or as it was pre-end stage liver disease and being listed for transplant. Having to accept this loss was not something that came easy for any of the patient participants, it was fought with persistence and independence. Brown et al. (2006)'s study on patients awaiting transplant described how reluctant patients were in allowing these changes to their lives. Similarly, Wainwright (1995) found patients and caregivers simply want to return to 'normal'. Furthermore, not only did their disease present them with physical limitations, many of their medications did too. Taking lactulose, one of the most commonly prescribed medications for liver failure

meant the need to be constantly near a bathroom, which was both limiting and embarrassing for the patients. Current research findings highlight how arduous it is for patients to slowly let go of their physical activities and joys (Bjork & Naden, 2008) and how they have to learn to take frequent naps and breaks between even the smallest of activities (Bjork & Naden, 2008, Brown et al., 2006, Wainwright, 1995).

In interpreting what the participants said, I found the concept of ‘normal’ was described as a return to their previous life and doing the things they once did; working, travelling, spending time with family and friends, caring for the home and helping looking after children. Normal appeared to be a taken for granted concept, one which was thought of on the surface, but not deeply questioned. The caregivers saw themselves as caregivers for the time being, and described how they would likely have to continue this role for 1 year post-transplant. They understood their spouse would not be perfectly healthy immediately after the transplant. For the caregivers, this meant there would be a perceived end date on their role as primary spousal caregiver, and that there would be a return to ‘normal’.

I found myself wondering if there could ever be a return to normal. Patients with end stage liver disease may never make a full recovery from their illness; most patients remain heavily monitored for the rest of their life. Throughout the narratives, it became evident that caregivers and patients alike agreed that the patient would not simply wake up after the transplant and no longer be the patient, or a ‘sick’ person. Parsons (1975), a sociologist, theorized about the role of a ‘sick person’, stating that illness is a dysfunction due to its impact on daily lives and the roles of individuals. Parsons theorized that when an individual takes on the role of a ‘sick person’, they no

longer have the responsibilities they once had, but are expected to try and find a way to solve or manage their illness. Although the participants all acknowledged the patient as being a 'sick person', Parsons' theory is challenged with the notion of transplantation. Transplanted patients often do not return to their previous health status, and must continue taking numerous medications and being continuously monitored. Furthermore, receiving a successful transplant is no guarantee for future health. Patients live with the constant threat that the organ may be rejected. For transplant recipients, this means finding themselves in a perpetual sick role, as they are confronted with endless medical tests, procedures and medications, while adjusting to losses in their life as a result of their illness (Oldbrisch, Benedict, Ashe & Levenson, 2002). This not only presents challenges for the patient as they attempt to return to a normal life, but also for caregivers. If their spouse remains in a perpetual sick role, the caregiver must continue to care for the spouse. For caregivers, this could mean fulfilling this role for the rest of their life. This does not coincide with what the caregivers in my study shared with me; I noted they saw their role as caregiver as having a definite end date. I noted that it would be beneficial for patients and caregivers to discuss the expectations of the caregiver post-transplant. Having these discussions could mean less ambiguity for both patients and caregivers, as they hopefully plan for their life post-transplant. Discussing what the future 'normal' would look like during the recovery from the transplant and after this period, could have positive implications for both patients and caregivers.

For many of the caregivers, caregiving meant taking over 'everything' and being left with the overwhelming burden of ensuring all aspects of the home and

family life were cared for. Caregivers saw the completion of these tasks as their role, despite how this impacted their life and personal health. This was a unique experience, not described by the patient participants. Caregivers saw it as their role as spouse and primary caregiver to ensure that everything and everyone was taken care of; regardless of what this meant for them. For the caregivers, this meant spending less time with friends and family, the inability to travel, increasing financial demands, a decrease in physical activities and recreational interests. Two out of four of the caregivers had children and worked outside of the home, making this role strain significantly more profound. Similarly, Kurz (2002) studied spouses caring for individuals awaiting heart transplant, and found there was more role strain for spousal caregivers who were employed. For the purpose of this study, caregiver role strain was defined as a caregiver's perceived difficulty in performing the family caregiver role (Doenges & Moorhouse, 2000). Furthermore, Kurz found that spouses were more likely to experience caregiver role strain if they felt they had difficulty in fulfilling their role. These findings are also consistent with the literature of spouses caring for individuals waiting for a heart transplant, as Mishel & Murdaugh (1987) found caregiver stress to be more significant when the family had young children. In their study, the younger patients with children felt catapulted towards illness and transplant, leaving them feeling less prepared for transplant and more victimized, leading to higher levels of stress. This higher level of stress may also be a result of the ill spouses being unable to do many of their previous activities, and the responsibility of the children that now falls solely on the spousal caregiver. For the caregivers with

young children living in the home, this meant being needed as a caregiver 24 hours a day, 365 days a year, which was undoubtedly challenging.

All of these roles, responsibilities and tasks left the caregivers with little to no time for themselves. This leads to an increase in distressing emotions, and the increased potential for caregiver burnout. I noted that although the caregivers in my study found these changes and new roles strenuous and all consuming; they felt a sense of pride in knowing they were doing it for the ill spouse and family. While many receive satisfaction with the role of spousal caregiver, others may not. Some may see caregiving for an ill spouse as a gift, while others may view it as an insurmountable burden (Riess-Sherwood, Given, Given, 2002). Dissatisfaction from the role could be a result of many things; the emotional distress caregivers often experience (Nijober, Tempelaar, Sanderman et al., 1998), depression (Braun, Mikulincer, Rydall, Walsh & Rodin, 2007) and the interference with paid employment (Scharlach and Boyd 1989, Covinsky et al., 2001 & Franklin, Ames, & King, 1994) among many other things. I found myself wondering if my role as a nurse and health care provider left the participants feeling as though they could not share feeling otherwise with me (i.e: unhappy, not proud). Knowing that pride helped bring positivity to the often difficult lives of these caregivers, I wondered how caregivers who do not feel a sense of pride in their care, viewed the care they provided. I pondered whether some caregivers could ever feel pride in the care they provided for their spouse, given that many of the caregivers in my study shared feeling inadequate. Research examining spouses of individuals waiting for heart transplant, found that spouses felt as though they had to take over everything

(McCurry & Thomas, 2002) and that the most difficult part was an increase in the number of tasks to be completed (Hwang, 1996). Caregivers of patients awaiting transplantation also related the need to relinquish former obligations and limit relationships with individuals outside of the immediate family (Saxe-Braithwaite & Chapman, 1992). Similarly, Casida (2005) found that spouses of individuals waiting for transplant go through numerous stages such as emotional distress, determination and optimism and that the caregiving role itself, places an overwhelming burden on the spousal caregiver.

Waiting for a liver transplant came with it a changed, renewed perspective for both patients and caregivers. Caregivers and patients alike thought of their world differently than they had prior to waiting for transplant. What had once mattered; cars, money, employment status, the opinion of others, physical finesse, trips and material things no longer mattered. What mattered now, was the time spent with family, and the time spent living the rest of their life to the fullest. Many of the participants found themselves wondering if each holiday or event would be the last together as a family, pushing the participants to appreciate each and every moment spent together. In interpreting what the participants said, I noted that this renewed perspective was something the participants were extremely proud of. They felt pride that they were able to take something positive out of such a horrible situation, and that despite the challenges, something good had come of their wait. Other research findings shared how patients worked to find meaning in their changed lives (Bjork & Naden, 2008) and how waiting and possibly facing death allowed them to step back, appreciate the little things and live for today (Brown et al., 2006). The little things

were regarded as things such as spending time with their spouse, family and friends. For many, it involved the once taken for granted moments; awaiting transplant made the patient participants realize they could no longer take many of these things for granted. Being on the transplant wait list meant there was no guarantee for the future; each passing day with the family could be one less they would experience if they did not receive the transplant. In thinking of their own mortality, patients in particular were able to better appreciate the life they were living and be happy with living for the moment. For many, this was something they had not done prior to being listed for transplant and realizing the uncertain future that lied ahead.

### **7.5 Light At The End Of The Tunnel**

In waiting for transplantation, both caregivers and patients identified how tumultuous the wait was emotionally, physically and mentally. Waiting came with many extreme emotions and experiences that neither patients nor caregivers could prepare for prior to being listed for transplant. Patients and caregivers recognized this wait could not be faced without significant resiliency and supports. The discussion that follows adds transparency to the theme, *light at the end of the tunnel*, through linking these findings to current research.

Enlisting supports, particularly those from others, came as a struggle for patients and caregivers. They wanted to avoid being a burden on others at all costs. In some ways, this was a contradiction for patients and caregivers, as they knew they needed the help and support of others to get through this time of waiting, yet wanted to maintain independency. I noted how challenging this was for both patient and caregiver; they struggled with asking for the help they needed from others. I found

myself wondering how for some, asking for help was seen as a weakness. For patients and caregivers, not being a burden meant doing all that they could to not be the focus of conversations and activities with family and friends. They did not want others to dwell on their problems, issues and concerns. Research suggests that patients awaiting organ transplant identify being a burden on others, and describe how they attempt to reduce this burden (Baker & McWilliam, 2003, Naef & Bourne, 2009, Bjork & Naden, 2008). Like those in my study, patients in these studies attempted to reduce this burden by doing all that they could themselves, regardless of the challenge. By attempting to reduce this burden on others, patients and caregivers alike often wound up unintentionally isolating themselves from their social networks and family members. Caregivers and patients often feel the need to diminish all former obligations and limit their relationships and activities with individuals outside of the immediate family circle (Saxe-Braithwaite & Chapman, Brown, Sorrell, McClaren & Creswell, 2006). Not only do patients and caregivers reduce their social commitments and activities in an effort not to burden or 'bring down' others, it is also in an effort to reduce time constraints.

Caregivers experienced coping with the wait for their spouses transplant differently than the patients in many ways. For caregivers, it was not only the wait for transplant they had to cope with and manage, but the associated stress that caring for their spouse carried with it. Although stress was not limited to the caregivers, the stress of 'doing it all' being unique to the caregivers became evident through comparing the experiences shared with me. It has been identified that caregivers experience equal or greater levels of distress when compared to cancer patients



(Langer, 2003), which highlights the significant level of distress caregivers experience. Alternatively, other research literature has shown there to be positive rewards, satisfaction and benefits from being a primary caregiver in the home (Kramer, 1997, Given, Given & Stommel et al., 1992). Giving caregivers the place and space to acknowledge both the positive and negative aspects they experience while caregiving may help them to more effectively cope with the negative experiences.

All of these roles, both new and old, left the caregivers often forgetting about their own needs; these were often placed on the back burner. This leads to an increase in caregiver role-strain; a state in which an individual experiences physical, emotional, social and/or financial burdens in the process of giving care to another (Carpenito-Moyet, 2012). Although many of the caregivers in the study acknowledged their many roles and responsibilities, they identified feeling helpless and an inability to do everything for both spouse and family. For these caregivers, this meant feeling as though they were incapable of providing everything for the ill spouse and family; leaving them in a position to feel significant caregiver role strain. Doenges and Moorhouse (2000) identified that spousal caregivers are imminently vulnerable for caregiver role strain if they perceive themselves as having difficulty fulfilling their spousal caregiver role within the family.

As a nurse and researcher, I found myself asking: Who cares for the caregiver? It became evident through the interviews that it was not the caregiver alone; they devoted all of their energy to the ill spouse. Without appropriate programs and services in place, caregivers may be left neglected, with the high possibility of

burnout, which has a significant impact on both caregiver and those they care for. As a health care system, we have placed family members, in particular spouses, in a position where it may be difficult to decline being a caregiver. At the same time, we have given little to no supports in order to assist these individuals in being a caregiver. Without intervention, the health and well being of caregivers may decline, leaving room for further research to be conducted at how to best support spousal caregivers.

Although not the case for the participants in my study, many individuals with a chronic illness may not be in a position to receive or give family or spousal care. Alternatively, Reid (2014) identifies that while some families share values and ties of affection that support family and spousal caregiving, some families are estranged; affected by histories, sexual orientation of politics. As health care providers, we must acknowledge that not all individuals may be in a place to give or receive this level of caregiving at home and must be willing to foster alternative forms of support.

Caregiving becomes a full-time, around the clock duty for individuals, leading to burden in addition to that already experienced by these individuals, as a result of the uncertain future of their spouse (Sabo, McLeod & Couban, 2013). This full-time job is challenging for all of the caregivers, but particularly those with jobs and daily responsibilities outside of the home (Casida, 2005). Not only did the caregivers attempt to relieve the burden on their spouse, they also attempted to reduce burden for other family members, such as children and parents of the ill spouse. Studies have revealed that caregivers experience strain as they attempt to alleviate the burden experienced by other family members (Kurz, 2002).

For caregivers, their faith and spirituality were seen as important coping mechanisms. The caregivers in this study repeatedly spoke of the importance of their faith and/or spirituality in finding the strength to wait for their spouse's liver transplant. Their belief in their faith and/or a higher spiritual power assisted them through their darkest thoughts and most challenging of days spent caregiving for their ill spouse. The caregivers found strength through this belief in a higher power or a 'god', and through frequent prayer, helping them to feel connected to their faith. For the caregivers, this meant putting their spouse's health in the hands of their higher power; it was through their faith they had their 'strong hold', while caregiving and waiting for their spouse's transplant. Although the wait for transplant was filled with uncertainty and anxiety, relying on their religious and spirituality brought with it a sense of peace and acceptance for caregivers. Caregivers in this study spoke of church, prayer, faith and spirituality; although these are three distinct concepts, each brought the participants a source of strength and closer to their spiritual world. Current research literature has identified the importance of religious / faith / spirituality support for individuals with or caregiving for someone with a life-threatening illness or surgical procedure (Jonsen, Athlin & Suhr, 2000, Haugh & Salyer, 2002, Brown, Sorrell, McClaren & Creswell, 2006, Bjork & Naden, 2008, Forsberg, Blackman & Moller, 2000, Albaugh, 2003, Livneh, 2000, Trimm, 1997). Providing psychosocial support and assistance with coping is not only beneficial to the health of caregivers, but also of their ill spouses they care for. Research has identified that the less perceived stress a caregiver experiences, the more of a source

of strength and assistance they can be for the patient (Friedman, 1992 & Bozett & Gibbons, 1983).

For patients and caregivers, the local transplant program was seen as a source of strength, and an outlet in which these individuals were able to utilize. This meant being able to turn to the staff at the transplant program, in particular the nurse coordinators when they had questions or simply needed to talk about their health or wait for transplant. In interpreting what the patients and caregiver said about the transplant program, I found the transplant program staff served as a valuable source of information. They saw staff members as having all of the information they needed, and as experts in liver disease requiring transplantation. Patients and caregivers quickly formed therapeutic relationships with the transplant staff; over time they viewed these individuals more like friends than hospital staff. When patients and caregivers felt their concerns were validated and the transplant program team answered their questions, they were able to more easily go about their wait. Patients in particular, found the team as a significant coping mechanism and source of strength; they felt there to be an 'open door' between themselves and the transplant program, despite their geographical location. Other research has discovered the importance of transplant program support and information during the wait for transplant (Jonsen, Athlin & Suhr, 2000, Haugh & Salyer, 2002, Brown, Sorrell, McClaren & Creswell, 2006, Bjork & Naden, 2008). Although not a finding for the participants in my study, Baker & McWilliams (2003) found that surveillance by transplant teams and enhanced rules of adherence to this came as a major stressor to patients waiting. Gaining a more in-depth understanding of how patients and families

interact with the transplant program could have positive implications for both patients and the health care providers that care for them.

Patients awaiting transplant described using their spouse and other family members as a significant source of support during the wait for transplant. Seeing resounding resiliency and strength from their spouse, allowed the patients themselves to be resilient in their wait for transplant. Resilience has been defined as the ability to withstand, overcome and rebound from adversity (Walsh, 1996). Utilizing the Family Resiliency Framework by Froma Walsh (1996) gave me a unique lens in which to interpret and begin to understand the experience of patients, caregivers and the family unit as a whole. Employing this framework guided me in beginning to understand how the outside influences of each family member impacts the coping and resiliency of the family as a whole. Walsh's framework helped me to understand how the developmental stage of the family impacts upon their ability to band together in times of adversity, such as that experienced by the caregivers and patients in this study. This led to my interpretation of how the experience of a family changes during adversity and the many supports that may assist a family in becoming and remaining resilient. Ultimately, utilizing this framework led me towards a more in-depth understanding of how a family can come together to overcome such a tumultuous time; waiting for a liver transplant, which impacted my interpretation of what they shared with me.

The patients in my study were aware of their substantial need for support; physically, emotionally, mentally; they found much of this support from their spouse and family members. In my interpretation of the patient's view of their spousal

caregivers support, I noted that patients highly appreciated and cherished the unrelenting support offered by their spousal caregiver. For these patients, the support provided by their spouse was imperative to their everyday life and wait for transplant, and could not be matched by other supports. Research has found that patients identify family and spousal support as being a crucial source of support while awaiting organ transplantation (Bjork & Naden, 2008, Naef & Bournes, 2009, Brown et al., 2006, Forsberg, Blackman & Moller, 2000).

While all of the patient participants were grateful for their spousal support, accepting this support came with challenges. Baker & William (2003) and Brown et al. (2006) found that patients awaiting liver transplant had to learn to surrender oneself to accepting resources for health. The patients in my study had to surrender their independence through many different avenues; their employment, driver's licenses and time alone. For these patients, this meant having to rely on their spouse for many things they themselves were once able to do, leading to feelings of helplessness. It meant letting go of control over many aspect of their life, leaving them feeling dependent on others and defeated. The moments in which the patients felt most helpless, they attempted to redirect their thoughts into the *conundrum of hope* that they would get the transplant, and their past abilities would be returned to them.

## **7.6 Riding The Emotional Roller Coaster Of Waiting**

Patients and caregivers in my study illuminated the roller coaster ride of emotions that waiting for a liver transplant brought to their lives. The complexity of end stage liver disease requiring transplant, and the emotional turmoil it brought to

patients and caregivers were revealed through the narratives. These experiences that were uncovered, and my interpretation of these, will be shared in the discussion that follows surrounding the finding of *riding the emotional roller coaster of waiting*.

Patients and caregivers came to understand liver disease and the need for transplant very differently from one another. With waiting, came a myriad of emotions; positive and negative that could not be avoided regardless of their efforts. The sheer act of being placed on the waiting list, brought with it countless emotions, such as anxiety, disappointment, fear, worry and happiness. For some, being placed on the waitlist was seen as the light at the end of the tunnel of a long experience with progressively worsening liver disease. The emotion of feeling as though being placed on the transplant list was the light at the end of the tunnel was also cited in the literature for patients awaiting kidney transplant (Moran, Scott & Darbyshire, 2011). For others, this placement confirmed the need for transplant for survival, which was devastating; one patient had maintained hope they would recover without the need for a liver transplant. These varying emotions with being placed on the waitlist are also found in the research literature, that found being listed for a liver transplant brings with it a multitude of emotions (Brown et al., 2006), and that many question whether they are really ill enough to require a liver transplant (Wainwright, 1997). In questioning whether they really needed the transplant, it appeared patients were in fear of what this would mean for them. This fear stemmed from knowing the surgery they would have to go undergo when they did receive a liver, and the long recovery following. For one participant in my study, questioning the need for transplant also appeared to come from a sense of denial. For this participant, accepting that she really

needed the liver transplant would mean accepting how sick she was, and that this illness would not go away. Accepting that she had irreversible end-stage liver disease was not something that could be accepted easily or without a considerable amount of time and support from her family. Although not found amongst patients in this study, other literature has identified that some patients question whether or not to be placed on the waitlist. In their study of patients awaiting liver transplant, Brown et al. (2006) found that some patients question whether the best part of their life was previously lived, and whether it was worth going through with the transplant. Understanding both perspectives is crucial, if we as health care providers want to understand the diverse waiting experience.

When patients and caregivers thought of where the liver they were desperately waiting for would come from, they experienced morally and ethically distressing emotions. All of the patients and caregivers knew that there was only way in which they or their spouse would receive a transplant; the death of another person who was an organ donor. Patients and caregivers struggled with knowing the often sudden, tragic death that occurred for donors. In interpreting what these patients shared, I noted that patients felt a sense of extreme distress within their desire for transplant. Patients wanted nothing more than to receive their potentially life-saving transplant, yet in doing so, found themselves inadvertently waiting for the death of another.

Waiting for the death of another has been shown to be both morally and ethically distressing for patients and caregivers awaiting transplant (Younger, 2003). This is a dilemma, as patients and families are left grappling with the reality that



another family must experience tragedy, leaving recipients and their families distraught, as they spend their time waiting for the often tragic death of another (Zink & Wertlieb, 2004). Sanner (2003) found that waiting recipients found it extremely unfair someone else had to die for them to live. This left the patients and caregivers with emotionally difficult thoughts, as they attempted to view the donation of another in a positive light. Although neither patients or caregivers spoke of this situation as being an ethical or moral dilemma, it can be regarded as one. In my interpretation I found myself with questions: It is moral for someone to wish for the death and demise of another in order to benefit oneself? Upon reflection I saw how some individuals might see this differently. Whether they were an organ donor or not, this individual died and it was through no fault of their own. Brown et al. (2006) found that even through liver transplant patients' anticipation and desire for a transplant, they realize this desire comes at the cost of another's life. Furthermore, Zink & Wertlieb (2004) found that patients and their families awaiting transplant grapple with the challenging reality that another family must experience tragedy, leaving recipients and their families distraught.

Getting an organ from another person was viewed as both a sacrifice and a gift by patients and caregivers. For caregivers and patients, the act of someone donating an organ to benefit their family was more than a gift, it was a sacrifice. The perception of this donated liver as a sacrifice emerged; patients saw the donation of this new organ, as being the 'ultimate sacrifice' for another. Although organ donation is frequently referred to as the 'gift of life' that reflects voluntarism and altruism on behalf of the donor (Chillag & Siminoff, 1999), others see it as a sacrifice. It is

viewed as a sacrifice, given that it is a very special kind of gift, and is a “particularly valuable, hard-wrought, hard-to-relinquish gift” (Mongoven, 2003, p.90). Caregivers were also aware of the magnitude of this sacrifice; they described how special the gift of a new liver was. They recognized this gift was not something they could purchase or give to their spouse, regardless of their desire. This presented as a challenge for the caregivers, as they felt helpless in their inability ‘to take away’ or ‘cure’ their spouses end stage disease.

A desire to extend the donor legacy existed for both the patients and caregivers. For patients and caregivers, this meant treating the new organ like a gift, and ensuring that it would not go to waste. This is consistent with the literature, that found the ability to extend a person’s legacy of caring for others, even after death has been found to be one of the most prominent reasons family decide to donate tissues and organs (Hogan, Coolican & Schmidt, 2013). Honouring the donor and their gift of life was something patients and caregivers felt compelled to do in accepting a donor liver. Doing so helped patients and caregivers to reconcile the truth that someone had to die in order for them to have a chance at life and survival. It became apparent that patients and caregivers valued taking care of the liver, and not taking life for granted or mistreating it in any way. Research literature suggests that individuals attempt to optimize health and life after transplant, as they see this as their responsibility in accepting this gift of life and showing gratitude (McCurry & Thomas, 2002, Forsberg, Blackman & Moller, 2000). In my interpretation of caregivers and patients perception of gratitude for their future donor and donor family, I noted that neither spoke of whether or not they would ever be grateful

enough for this donor organ. I found myself wondering if someone ever could demonstrate this gratefulness when being given something as monumental as a liver. This concept is discussed in other research literature, that shares recipients of organs can feel a lifelong indebtedness to their anonymous donor family (Swayze & Fox, 1992, Mauss, 1954). Mauss (1954) saw that in receiving an organ, a gift', the recipient and their family would feel the need to repay this deed, and if they did not adequate repay or repay sufficiently; they would feel a loss of self-esteem. Thus, Mauss saw accepting an organ as creating a lasting sense of indebtedness, whereby the recipient would have to find a way to repay this gift in a meaningful way.

The emotions that came with waiting for a liver transplant interfered with the daily lives of both patients and caregivers. Study participants saw the emotions of waiting as inevitable and inescapable; something they had to learn to accept. Waiting meant experiencing endless emotional ups and downs; many of these being depressive and draining physically and mentally for the patient. For patients, waiting was frustrating, draining unbearable, long, filled with uncertainty, loss and fear, boring and a time of questioning oneself and the life they have lived. Research studies have found waiting to be filled with uncertainty (Bunzel, Wollenek & Grundbok, 1992), loss (Brown et al., 2006), emotionally draining (Larsson, Hedelein & Athlin, 2007) and ambiguity (Bournes & Mitchell, 2002).

Patients shared how waiting left them feeling frustrating, inferior, upset and unlike their 'old self'. In my interpretation, I noted that the time spent waiting was not static; one day could be perceived positively, while the next day could be the most challenging day of their entire lives, often with no rhyme or reason. For patients and

caregivers, this meant having to live in a state of uncertainty and chaos, not knowing what the next day would bring or how the day ahead would unfold. This was particularly draining for the caregivers; they could not plan even one day ahead, as they would not know whether or not their spouse would be up for it. It became apparent to me that this lack of control was enough to take over the lives of the caregivers and patients. This reality of waiting left caregivers and patients living in a constant state of uncertainty, where both were left feeling helpless against the physical and mental limitations they experienced. Alternatively, other studies have shown that waiting for transplant leaves some patients feeling mentally strong (Bjork & Naden, 2008).

For both patients and caregivers this meant no matter how hard they tried, nothing could change the disease process of timing or when a transplant would finally arrive. This uncertainty extended into all aspects of the life for patients and caregivers, impacting upon many of the decisions they made in life. Research studies have found that patients, caregivers and their families struggle with the uncertainty and fear of the uncertain future that waiting brings to their lives (Brown et al., 2006, Jonsén, Athlin and Suhr, 2000, Bjork & Naden 2008, Johnson & Hathaway, 1996, Bean, 2005, Lumby, 1997, Forsberg, Backman & Moller, 2000, Wainwright, 1997, Moran, Scott & Darbyshire, 2011, Pelletier, 2008).

Protecting the children and other family members was seen as a priority for patients and caregivers. End stage liver disease was not limited to the one individual experiencing it; it was a family disease that imprinted upon each and every member of the family. For the patients and caregivers, this meant sheltering the children and

elderly parents from the harsh realities of the disease and the uncertainty of the future. At the same time, they shared with me how they did not want to provide false information to their children, and found themselves in a balancing act. Patients and caregivers struggled with how much information to give children and elderly parents, as they wanted to be truthful, but did not want to share “too much”. As adults and parents, their role was to bear the emotional hardship and to protect others from experiencing this at all costs. I noted that the desire to protect the children by the patient was very similar to the desire the caregivers had in protecting the spouse. Just as the caregiver wanted to shelter their ill spouse from their negative emotions and feelings, the patients wanted to shelter the children. Both the patient and caregiver parents saw themselves as the only individuals that should experience negative emotions as a result of the patient’s illness and wait for transplant. For the participants, this meant buffering this information from the children, in order to protect them from the difficult, uncertain reality of their parent’s illness. They did not feel it was a child’s role to bear the hardship of the wait for transplant and liver disease; keeping the information they shared minimal, helped parents to feel as though they were adequately informing their children, while protecting them. Ultimately, for the parents in this study, this meant they could not completely take away their children’s worry, but could decide what to share with them and what to protect and buffer them from.

Patients and caregivers not only experienced uncertainty in relation to what the days ahead would bring or what they would be able to do with these days, but also with regards to if these days would come. Through living within the *conundrum of*

*hope*, patients and caregivers were aware of the risks and possibilities of the uncertain future. The notion of death being a possibility as a result of the transplant surgery, led to a wide array of emotions for both patients and caregivers. Patients and caregivers were left feeling uncertain, fearful, worrisome and anxious over when, or if the transplant would occur, and the result of the surgery if they were lucky enough to receive a liver. This meant that learning of a suitable match for transplant did not come with it the guarantee that they would get better; in fact the surgery itself came with tremendous risks, including death. Bjork & Naden's (2008) research study on patients awaiting liver transplant, found that many patients awaiting transplant see death as a realistic possible outcome. This reality leaves patients and caregivers with two significant "ifs". They are left wondering if they or their spouse would receive the transplant, and if it would be successful. Other literature on patients and caregivers awaiting cardiac transplant, found the question of "if" a transplant would become available was a major source of stress for those awaiting transplant (Christopherson, 1987, Weems & Patterson, 1989). Furthermore, Cresp-Gerrard (1993) related that for some, awaiting transplant and being on the list is like being on "life row", where they are constantly reminded of their mortality. Over time, several of the participants in my study were able to more effectively cope with the uncertainty that waiting brought to their lives. I noted that it was the caregiver whose spouse had been waiting the longest who appeared to be the most at ease with the uncertainty of waiting for transplant, suggesting possible ease with acceptance over time.

This uncertainty for the future led to an array of negative emotions, which

put patients and caregivers on an emotional roller coaster, as they attempted to remain hopeful that they would get a suitable liver, and that the liver would be successful. For many of the participants, keeping this hope was the only option they saw for themselves; to contemplate the alternative - death, was too painful. Although many of the participants did not speak about death, as it was seen as being too painful to contemplate; I interpreted that they were not in denial of the real possibility of this. All of the participants knew and understood the risks, but only some chose to give the possibility of death real thought. Those who did not contemplate death saw positively thinking and hoping for the desirable outcome of a return to health as the only option. This appeared to leave these individuals feeling happier and less emotionally drained by the uncertainty. Not contemplating death extended beyond the fear of death; it meant remaining experiencing the *conundrum of hope* that a successful liver transplant would occur.

Expressing the countless emotions they experienced during their wait was seen as a priority for many patients. For the patients in this study, holding in all of the emotional turmoil they were experiencing was just too much; they needed to express themselves. Expressing their emotions was about being heard, getting their feelings off of their chest and learning to effectively cope with the mental and emotional difficulties they experienced. Patients in this study acknowledged how unpredictable their emotions were, and how it was often through the expression of these emotions that they were able to get through the wait. For many of the patients in this study, crying was the ultimate release of emotion. Although crying itself is often viewed negatively, for these patients it was seen in a positive light. Research suggests that

patients awaiting transplant are often overwhelmed with feelings of sadness and tears (Kurz, 2002, Forsberg, Blackman & Moller, 2000). Alternatively, Robertson (1999) found that the physical problems experienced when waiting interfered with the ability to address the psychological aspects of waiting. For others, talking about their emotions and their experience helped them to cope with the arduous emotions that they experienced.

Although there are many similarities between the emotions experienced by patients and caregivers in the wait for transplant, there are also considerable differences. Being a caregiver often meant not having the opportunity to share their emotions with others, as the patient participants were usually viewed as the focus in the wait for transplant. Caregivers saw it as their role to provide care for the ill spouse and the entire family, and were very rarely, if ever, given the chance to talk about their own emotions and how this wait impacted their life. All of the caregivers shared being happily married to their ill spouses, and that they withheld expressing their emotions related to liver disease and their experience of the wait for transplant to their spouse. In doing so, caregivers were attempting to protect their ill spouse from their own negative emotions they experienced.

For caregivers, caring for their spouse awaiting transplantation meant riding on an emotional roller coaster, filled with many unexpected ups and downs. This was not unlike the experience of the patients, however one primary difference existed. Caregivers lived with the constant fear that their spouse may not make it to transplant, or may die as a result of their transplant. They described living in constant fear and worry about the health and well-being of their spouse; often flooding their thoughts



when they left the house or knew the ill spouse was alone. This created a constant fear in the mind of the caregiver; they could not help but picture the worst-case scenario. Although the caregivers attempted to avoid thinking of the worst-case scenario where they would find themselves without the ill spouse, it was difficult to prevent their mind from going there. For caregivers, this meant wondering what would happen to them if their spouse did not survive the wait for transplant, and where this would leave them and their family. All of the caregivers in this study had devoted their life to caring for the ill spouse, and imagining a life without them was unfathomable. The loss of their spouse would mean having to pick up the pieces of their life, and this was not something they could imagine having to do. To attempt to relieve these negative thoughts, caregivers thought of happier times, helping them cope with the idea of the worst-case scenario. Other studies have found that for many spousal caregivers, their greatest fear was that their spouse would die before a suitable donor could be found (Collins, White-Williams & Jalowiec, 1996, Kurz, 2002).

In examining what the caregivers were sharing with, I began exploring whether there were significant differences in caregiving among the female and male caregivers in my study. Historically, the stereotype has remained that females are traditionally the caregivers for the husband, children and the parents, as they are often viewed as being more nurturing, motherly and caring. Although I did not find the emotional response of caregivers to vary significantly by gender, one of the male caregivers highlighted the difficulty he experienced in ensuring he was providing adequate care physically and emotionally for his wife. As a caregiver, a busy working

husband and father; he constantly worried if he was doing enough for his wife. The literature highlights that when their wife is sick, male caregivers begin to redefine their perceived purpose in life as being not solely limited to their work role (Kramer & Lambert, 1999). Being a spousal caregiver for him, meant caring for all aspects of his wife, children and home; financially, physically, emotionally and mentally. In doing so, he remained hopeful that his time and energy spent being a family caregiving for all would pay off and that his wife would have a successful transplant.

Although the research literature indicated that many female caregivers experience greater role strain than male caregivers (Keating, Fast, Frederick, Cranswick & Perrier, 1999, Bedard et al., 2005, Brazil, Thabane, Foster & Bedard, 2009), in my interpretation I did not note there to be any differences in the perceived role strain between the male and female caregivers in my study. The perceived role strain I interpreted had less to do with the gender of the caregiver, and more to do with the health status of the spouse they were caring for. A higher level of role strain and burden existed for the two caregivers who worked outside of the home and had young children living in the home. It appeared as though the developmental stage in which the family was in significantly impacted their experience of waiting, as described in my chosen theoretical framework by Walsh (2003). The caregivers in my study with young children appeared to have more responsibilities; emotionally, mentally, physically and financially than those with grown children outside of the home. The wait also appeared more strenuous on the caregivers with young children, as they contemplated their life if the ill spouse were to pass away. This led to a higher level of role strain for these caregivers, as they strived to do it all. This is consistent

with the literature that highlighted caregivers with young children were more likely to report role strain (Mishel & Murdaugh, 1987) and those who were employed outside of the home (Kurz, 2002).

### **7.7 In Summary**

This chapter has provided a discussion of the four themes identified throughout the seven interviews conducted with patients and caregivers awaiting liver transplant. It has highlighted the similarities and differences in how patients and caregivers experience the wait for a liver transplant. Waiting for the Phone Call, Light at the End of the Tunnel, Riding the Emotional Roller Coaster of Waiting and Negotiating the Disruption: Redefining Self were identified as being core themes in both the caregiver and patient experience of waiting for a liver transplant. Threaded throughout these was the overarching theme of the *Conundrum of Hope*, where despite their situation or wait, caregivers and patients remained resoundingly hopeful that a viable transplant would come, and that it would be successful. In giving a voice to the patients and caregivers by conducting these interviews, the lived experience of waiting for a liver transplant was illuminated. This study provides a greater understanding of the lived experience of not only patients, but also caregivers as they live through the uncertain future of waiting for liver transplant.

## **Chapter 8 Conclusion**

### **8.1 Moving Beyond The Findings**

Understanding the lived experience of patients and caregivers awaiting liver transplant has significant implications for those who experience this wait, and the health care providers who care for them within the health care system. Patients and caregivers in this study identified the unique experience of waiting for a liver transplant, and how this affected their everyday lives. Patients and caregivers had many different experiences, as well as similarities in the way in which they experienced this wait. The findings that emerged from this study highlight the experience of waiting for a liver transplant for both patients and caregivers, as well as how waiting informed every aspect of their lives. A significant gap exists within the research literature on not only patients and caregivers awaiting liver transplantation, but on waiting within the context of other solid organ transplant or for health care in a broader context. Without an understanding of the experience of waiting beyond that associated with calendar time (e.g., wait times, time to treatment), the provision of care will fail to meet the holistic needs of patients, their caregivers and families. We may miss the opportunity to care for the ‘whole’ patient and family if we do not acknowledge the need to care for the psychological and psychosocial needs, in addition to the complex physical requirements of care.

Four core themes were identified in this study that embodied the experience of waiting for a liver transplant for patients and caregivers. While there were differences among patients and caregivers, four core themes existed within both groups. Patients and caregivers identified waiting for the phone call that a transplant was available as

being one of the most arduous aspects of their wait for transplant. Both groups described the emotional roller coaster ride of emotions that they found themselves on whilst waiting. Being a patient and caregiver also brought with it the need to negotiate many changes to their lives, leading to a disruption of self. Furthermore, patients and caregivers described the many sources of strengths they had in their lives, and how getting the transplant was viewed as the light at the end of the tunnel, ultimately helping them through their wait. All of these four commonalities were embedded within the overarching finding of the *conundrum of hope*. In their wait for a liver transplant, patients and caregivers remained hopeful that despite the setbacks, challenges and struggles they experienced, that their future would be positive.

## **8.2 Study Strengths And Limitations**

This qualitative research study offers a rich description and interpretation of the meaning patients and caregivers in Atlantic Canada waiting for a liver transplant assign to the experience. The phenomenon has not been previously studied among this population in Atlantic Canada reinforcing the need for more research on the phenomenon of waiting. While generalizations cannot be made, the findings add to existing research exploring patients and caregivers waiting for a variety of organ transplants. The findings from this study begin to form a foundation on which future research can be built by challenging current knowledge and understanding around the experience of waiting for a liver transplantation. Taking an interpretive phenomenological approach was instrumental in uncovering how and in what way a small group of study participants (three patients, four caregivers) attempted to make sense of, assign meaning to and live out the experience of waiting for a liver

transplant. The small sample size comprised 40% of the families actively listed on the waitlist at the time of recruitment; involved participants from across two Atlantic Canadian provinces; reflected both rural and urban settings. Although it is not uncommon for many qualitative studies to reflect a female perspective, this study was able to provide a ratio of 4:3 (female to male) permitting a more inclusive gender perspective. A limitation of the study was the lack of non-spousal caregiver perspectives which may have been helpful in more fully reflecting how and in what way caregiving is lived out within the context of waiting for a liver transplant. It would be reasonable to expect non-spousal caregivers to face different challenges from those of spousal caregivers for a variety of reasons including the difference in context, quality and nature of the relationships prior to caregiving. The existing relationship between caregiver and patient has significance for how and in what way individuals and families process, assign meaning and adjust to illness.

Spousal caregiving is a unique position for caregivers and patient, differing from other forms of informal caregiving for numerous reasons. It is unique, in that it emerges from a reciprocal relationship where individuals have historically, a shared responsibility in caring for one another's welfare (Spaid & Barusch, 1994). Spousal caregiving is the second most common form of informal caregiving, having a slightly lower occurrence than parental caregiving by adult children (Georgetown University Center on an Aging Society, 2005). For recipients, research has shown spousal caregiving to be preferred to that of other informal caregivers, despite the negative effects that have been shown for these spousal caregivers (Taylor, Kuchibhatla, Ostbye, Plassman & Clipp, 2008, Schulz & Beach, 1999). Although reasons may vary

among individuals, reasons for a spouse to be the preferred caregiver for many may be their increased comfort level with the individual and comfort in having them in their home. As health care providers, we must be cognizant of the potential for relational difficulties in spousal relationships, such as communications issues and interpersonal conflict, as spousal caregivers are more likely than non-spousal caregivers to experience relational difficulties with their spouse they are caring for (Beech et al. 2005). We cannot assume that all spousal relationships are in a position to, or willing to accept the change from reciprocal relationship to that of patient-caregiver. Within the health care system, we must be open to different care arrangements, including those that do not include well spouses caring for one another. We must also be open to creating and managing arrangements for individuals who do not have an identified spousal caregiver living in their home.

The vast majority of research on chronic illness spousal caregiving has left out the impact of stressful caregiving relationships, focusing on stresses of care demands and functional losses (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Malloy, 2011). While the majority of spousal caregiving research has been conducted on spouses caring for a spouse with Alzheimer's disease or dementia (Schulz & Martire, 2004), these findings can help to provide an understanding of how spousal caregiving affects spouses. Findings on spousal caregivers of individuals with dementia, have found there to be a loss of relationship with the ill spouse, tensions within the relationship and care decision conflicts within the relationship, all affecting the existing spousal relationship (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Malloy, 2011). Although helpful, the lack of literature on the patient-caregiver relationship examining younger

populations experiencing chronic disease and/or cancer such as end-stage liver disease leaves a gap in our research literature and understanding. As a result, further research studies are required for us to have an in-depth understanding of the distinctive changes that spousal caregiving can bring to existing spousal relationships.

This study examined the experience of patients and caregivers at one transplant center in Canada, drawing patients from across Atlantic Canada. It would be beneficial if future studies could be conducted across multiple transplant centers in Canada to provide further insight into the experiences of patients and caregivers awaiting liver transplant across Canada.

Both a strength and limitation of this study may have been my role as both researcher and Registered Nurse. Individuals may feel safe and confident entrusting their experiences to a Registered Nurse. Alternatively, although I do not work within the transplant program at the hospital they frequent, the participants may have felt compelled to share positive experiences with me and may have been reluctant to share potentially negative experiences related to their experiences of waiting. However, being a nurse helped with the co-creation of understanding that is important in an interpretive phenomenological study such as this, and my experiences helped to create my interpretation of what the participants shared with me (Benner, 1994). This co-creation, a cornerstone of phenomenology is important; through this I bring my awareness of the experience of waiting which has been created through my own life experiences as both a person in the world and a Registered Nurse. My past experiences caring for patients and families prior to, during and post-transplant all contributed to my understanding and interpretation of the research findings.



### 8.3 Relevance Of Study Findings

The findings from my study highlight the need for a greater, more in-depth understanding of how patients and caregivers experience the wait for transplant. Furthermore, this study underscores the need for there to be further supports offered (e.g., psychological support services, support groups, more frequent check-ins) patients and caregivers while they await liver transplantation. The participants shared how the *conundrum of hope* informed their experiences of waiting, and how despite their darkest, most challenging of days they remained hopeful that a transplant would take place. Findings from this study highlighted numerous areas for growth and improvement within the health care system for patients and caregivers.

#### 8.3.1 Practice, Education And Research Implications

Patients and caregivers in this study identified significant emotional and mental turmoil associated with waiting for a liver transplant. Much of the emotional and psychological turmoil stemmed from the uncertainty of not knowing when, or if a liver transplant would become available. Participants were challenged by the lack of control over the process, particularly when a liver would be available and the inability to plan for their future. Although the participants had access to a transplant social worker and psychologist, there were no pre-scheduled appointments or “check-ins” for patients listed on the transplant wait list. The participants believed that uncertainty was a natural element of waiting, and that this was something they had to deal with, despite how challenging this became.

Research has shown that high levels of uncertainty have been linked to increased emotional distress, depression and anxiety for individuals experiencing

chronic and life threatening illnesses (McCormick, 2002, Mishel, 1999, Bailey, Wallace & Mishel, 2007). Health care providers (nurses, physicians, social workers, psychologists and other allied health professionals) need to both acknowledge and assess for uncertainty. Having health care providers address their uncertainty could lead to the ability to more effectively integrate meaning and limit the influence uncertainty of their illness has on their lives, instead of viewing it as a threat Mishel (1981).

Patients and caregivers in this study identified feeling hopeful that a liver would be become available and the outcome successful. Suggestions to help support patients and caregivers emotionally mentally, psychologically and physically during of the wait include:

1. Assisting and educating health care providers in how to engage in ‘difficult’ conversations with patients and families. While health care providers identify 57% of emotional cues from patients, they respond to only approximately 22% (Kennedy, Sheldon, Hillaire & Berry, 2011). Reasons for the limited response to appear to arise out of a fear amongst health care providers that talking about death or other end of life issues may diminish hope in the patient and their family (Betcher, 2010). Health care providers may also lack the time required to have difficult conversations with patients and families (Hancock, Clayton, Parker et al., 2007). Without this education on the importance of these conversations, health care providers may find it easier to revert to societal expectations of maintaining an optimistic outlook. The failure to attend to such conversations may also be a reflection of the environment within which care is delivered – such care is rooted

in a biomedical approach which perceives the lack of a positive outcome as a failure. The health care system needs to foster places, spaces and time to be available to patients, families and caregivers to have these challenging conversations and to share their fears, worries and emotions, even when they are not positively hopeful.

Patients must feel comfortable speaking with their health care providers about their concerns including the illness, prognosis, outcomes and future. Similarly, patients may also avoid initiating these difficult conversations about death or end of life with health care providers. Research has cited many reasons for why patients and families avoid initiating these conversations, including perceptions that the healthcare providers are too busy, the patient themselves not wanting to upset their family members or caregivers and fearing that these conversations are not appropriate at a particular point in their illness (Barnes, Barlow, Harrington et al. 2011& Hofmann, Wenger, Davis et al. 1997).

2. Increased access to psychological supports other than those that exist more informally through transplant social workers and psychologists. Scheduled periodic visits with psychological transplant staff (psychologists, nursing, etc.) would also be beneficial throughout the waiting trajectory, instead of only having one mandatory visit with the psychologist during workup for transplant. This may address any increase in depression, anxiety or other psychological concerns by both the patient and health care provider. The transplant program could create a guideline to ensure that all patients and caregivers are seen at periodic intervals (e.g., every 3 months) while on the liver transplant waitlist. Guidelines could be

developed that permit flexibility with check-ins offered in-person, by telephone or other innovative means. Additionally, patients and caregivers need to be able to select the level of psychological support offered during this time and their frequency (e.g., if feeling distressed could be seen sooner than 3 months). The creation of a guideline may ensure that patients, caregivers and family members who are waiting for transplant have the opportunity to connect with transplant staff throughout the waiting journey, not solely upon listing and post-transplantation.

3. Online support communities could be created which may address the significant geographical constraints experienced by this population, given that the Atlantic Multi Organ Transplant Program services individuals in four provinces. Early data on online support groups has shown such groups to be helpful in connecting individuals with larger numbers of individuals with similar health concerns (Walther & Boyd, 2002). They also allow patients to connect with others they would ordinarily be unable to due to geographical barriers (Robinson & Turner, 2003, Chung, 2014). These groups could be moderated by a member of the transplant staff in Halifax, but could also involve interested past liver transplant recipients, as is done in other centers in Canada. Other transplant centres in Canada who are successfully running these programs could assist with this facilitation and creation of these groups.
4. Creating a support system or access to services for caregivers, who in our current system, are often left without a voice. These include supports for not only both patient and caregiver together, but also caregivers separately. These could include

increased access to transplant psychologists and social workers, and also facilitated caregiver online support groups for. Caregivers experience physical, emotional, financial and psychological burdens, which can ultimately affect their quality of life (Eatmon, 2002 & James, Daniels, Rahman, McConkey, Derry & Young, 2007). Online support groups would be particularly helpful, given that approximately 59% of all family caregivers are employed (Giovannetti, Wolff, Frick, Boulton, 2009). Results from research on online support groups specifically for caregivers have shown a decrease in depressive symptoms and an increase in quality of life for caregivers who participate in such groups (Klemm, Hayes, Difenbeck & Milcarek, 2014).

5. Creating a 'buddy system' in which past recipients could connect electronically, by mail or in person with individuals currently on the waitlist, which is currently being offered in other transplant centers in Canada. Peer mentors or 'buddy systems' may be helpful for patients, as they provide patients with the opportunity to speak to other who have experienced their disease, which may help to validate their concerns, thoughts and experiences. From an experiential perspective, peer mentors have the potential to provide supports that family or caregivers may be unable to provide. Peer mentor programs have been shown to be particularly successful in rural or geographical constrained areas, where frequent visits with health care providers are difficult or inaccessible (Long, Jahnle, Richardson, Loewenstein & Volpp, 2012).

In light of the findings from this study, future studies should be conducted to examine the experience of waiting for other organ transplants (heart, kidney, lung,

pancreas etc.) in a variety of transplant centers across Canada. Larger sample sizes are needed to increase our understanding of the experience of these patients and caregivers, their similarities and their differences. At the same time, large sample sizes may prove challenging given the limited number of individuals on the wait list at any one time. Furthermore, future studies could be done with patients and caregivers awaiting various transplants to further explore the overarching theme of *conundrum of hope* and to determine whether this is a shared experience of awaiting an organ, or health care services as a whole. Future studies would be helpful in more clearly conceptualizing this conundrum of hope and its possible applicability across other chronic, life-limiting diseases.

#### **8.4 Final Thoughts**

This study provides a unique perspective of how patients and caregivers experience the wait for a liver transplant in Atlantic Canada. Through the use of an interpretive phenomenological design, the voices of study participants, in particular the caregivers, emerged illuminating how waiting is experienced beyond that of the traditional clock or disembodied time. The participants' experiences shared in this study may help us question, our current attitudes, values and beliefs of how waiting is lived out and meaning assigned to the experience of waiting within the context of liver transplantation.

These findings show there to be a need for further research and supports for patients, caregivers and families awaiting transplantation. Finally, understanding what it means to be a patient or caregiver awaiting transplant may provide insight how into

we can best support and enhance the inevitable period of waiting experienced following listing for transplantation.

## References

- Abeloff, M., Armitage, J., Lichter, A., & Niederhuber, J. (2000). *Clinical Oncology*, 2nd edn. Churchill Livingstone, New York.
- Aday, L. (1996). *Designing and conducting health surveys* (2nd ed.). San Francisco: Jossey-Bass.
- Albaugh, J. (2003). Spirituality and life-threatening illness: A phenomenological study. *Oncology Nursing Forum*, 30(4), 593–598. doi: 10.1188/03.ONF.593-598.
- Anselm, A., Palda, V., Guest, C., McLean, R., Vachon, M., Kelner, M., et al. (2005). Barriers to communication regarding end-of-life care: Perspectives of care providers. *Journal of Critical Care*, 20, 214-223.
- Arbour, R. (2012). Confounding factors in brain death: Cardiogenic ventilator autotriggering and implications for organ transplantation. *Intensive & Critical Care Nursing*, 28(6), 321-328. doi:10.1016/j.iccn.2012.03.003.
- Armstrong, P., & Armstrong, H. (2004). *Thinking it through: Women, work and caring in the new millennium*. In Grant, K.R., Amaratunga, C., Armstrong, P., Boscoe, M., Pederson, A., & Willson, K. (Eds.), *Caring for/caring about: Women, home care and unpaid caregiving*. (pp. 5-45) Aurora: Garamond Press.
- Askari, F. (2007). *Hepatitis C: The Silent Epidemic*. Perseus Publishing: Cambridge, MA.
- Averill, J., Catlin, G., & Chon, K. (1990). *Rules of hope*. New York: Springer-Verlag.
- Bailey, D., Wallace, M., & Mishel, M. (2007). Watching, waiting and uncertainty in prostate cancer. *Journal Of Clinical Nursing*, 16(4), 734-741. doi:10.1111/j.1365-2702.2005.01545.x.
- Baker, M., & McWilliam, C. (2003). How patients manage life and health while waiting for a liver transplant. *Progress In Transplantation*, 13(1), 47-60.
- Barnes, K., Barlow, C., & Harrington, J, et al. (2011). Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. *Palliative Support Care*, 9,73-79.
- Banonis, B. (1989). The lived experience of recovering from addiction: a phenomenological study. *Nursing Science Quarterly* 2(1), 37-42.



- Bandura, A. (1988). Self-regulation of motivation and action through goal systems in V Hamilton, GH Bower, N Frijda (Eds.), *Cognitive perspectives on emotion and motivation*, Kluwer Academic Press, Dordrecht, 37–61.
- Barnes, K., Barlow, C., Harrington, J., et al. (2011). Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. *Palliat Support Care*, 9(1), 73–79.
- Bean, K. (2005). An exploratory investigation of quality of life in adult liver transplant recipients. *Progress in Transplantation*, 15, 392-396.
- Bean, K., & Wagner, K. (2006). Self-transcendence, illness distress, and quality of life among liver transplant recipients. *Journal of Theory Construction & Testing*, 10(2), 47-53.
- Beckham, J., Rice, R., Talton, S., Helms, M., Young, L. (1994). Relationship of cognitive constructs to adjustment in rheumatoid arthritis patients. *Cogn Ther Res*, 18, 479–496.
- Bédard, M., Kuzik, R., Chambers, L., Molloy, D. W., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women care givers: The contribution of care recipient behaviour problems. *International Psychogeriatrics*, 17, 1-20.
- Beech, S., Schulz, R., Williamson, G., Miller, S., Weiner, M., Lance, C. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society*, 53(2), 255–261.
- Benner, P. (1994). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*. Thousand Oaks, CA: Sage Publications.
- Betcher, D. (2010). Elephant in the room project: Improving care efficacy through effective and compassionate communication with palliative care patients. *Medsurg Nursing*, 19. 101-105.
- Bhugra, D., & Becker M., A. (2005). Migration, cultural bereavement and cultural identity. *World Psychiatry*, 4:18–24.
- Bjørk, I., & Nåden, D. (2008). Patients' experiences of waiting for a liver transplantation. *Nursing Inquiry*, 15(4), 289-298.
- Blanch, J., Sureda, B., Flavia, M., Marcos, V., de Pablo, J., De Lazzari, E., et al. (2004). Psychosocial adjustment to orthotopic liver transplantation in 266 recipients. *Liver Transplantation*, 10(2), 228-234.

- Bournes, D. A., & Mitchell, G. J. (2002). Waiting: The experience of persons in a critical care waiting room. *Research in Nursing & Health*, 25, 58-67.
- Bozett, F., & Gibbons, R. (1983) The nursing management of families in the critical care setting, *Critical Care Update*, 10, 2:22–24.
- Brazil, K., Thabane, L., Foster, G. & Bedard, M. (2009). Gender differences among Canadian spousal caregivers at the end of the life. *Health and Social Care in the Community*, 17(2), 159-166.
- Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: spouse caregivers. *Journal Of Clinical Oncology*, 25(30), 4829-4834.
- Brenner, G., Melamed, B., & Panush, R. S. (1994). Optimism and coping as determinants of psychosocial adjustment to rheumatoid arthritis. *Journal of Clinical Psychology in Medical Settings*, 1,115–134.
- British Columbia Transplant. (2014). Criteria for Donation. Retrieved from [http://www.transplant.bc.ca/odr\\_criteria\\_main.htm](http://www.transplant.bc.ca/odr_criteria_main.htm).
- Brocken, P., Prins, J., Dekhuijzen, P., & van der Heijden, F. (2012). The faster the better? A systematic review on distress in the diagnostic phase of suspected cancer, and the influence of rapid diagnostic pathways. *Psycho-Oncology*, 21(1), 1-10.
- Brown, J., Sorrell, J., McClaren, J., & Creswell, J. (2006). Waiting for a liver transplant. *Qualitative Health Research*, 16(1), 119-136.
- Bruce, T., Bowman, J., & Brown, S. (1998). Factors that influence patient satisfaction in the emergency department. *Journal of Nursing Care Quality*, 13(2), 31-37.
- Bunzel, B., Wollenek, G., & Grundbock, A. (1992) Psychosocial problems of donor heart recipients adversely affecting quality of life. *Qual Life Res* 1:307–313.
- Burker, E., Evon, D., Ascari, J., Loiselle, M., Finkel, J., & Mill, M. (2006). Relationship between coping and depression in heart transplant candidates and their spouses. *Progress In Transplantation*, 16(3), 215-221.
- Buse, S., & Pieper, B. (1990). Impact of cardiac transplantation on the spouse's life. *Heart Lung*, 19: 641-648.
- Butler, S., Turner, W., Kaye, L., Ruffin, L., Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work*, 46(1):47–63.

- Butt, G., Paterson, B., & McGuinness, L. (2008). Living with the stigma of hepatitis C. *Western Journal of Nursing Research*, 30(2), 204-221.
- Butterworth, P., Pymont, C., Rodgers, B., Windsor, T. D., & Anstey, K. J. (2010). Factors that explain the poorer mental health of caregivers: Results from a community survey of older Australians. *Australian and New Zealand Journal of Psychiatry*, 44(7), 616–624. CA: Sage Publications.
- Caccamo, L., Azara, V., Doglia, M., Sessini, M., Rossi, G., Gala, C., et al. (2001). Longitudinal prospective measurement of the quality of life before and after liver transplantation among adults. *Transplant Proceedings*, 33(1/2), 1880-1881.
- Caine, V., & Estefan, A. (2011). The experience of waiting: Inquiry into the long-term relational responsibilities in narrative inquiry. *Qualitative Inquiry*, 17(10), 965-971.
- Canadian Liver Foundation (2013). Liver Disease. Accessed on August 7<sup>th</sup>, 2013 at <http://liver.ca/liver-disease/>.
- Carpenito-Moyet, L. (2012). *Nursing diagnosis: Application to clinical practice* (14th ed.). Philadelphia, PA: Lippincott, Williams, & Williams.
- Casida, J. (2005). The lived experience of spouses of patients with left ventricular assist device before heart transplantation. *American Journal of Critical Care*, 14, 145-151.
- Catania, C., De Pas, T., Minchella, I., et al. (2010). "Waiting and the waiting room: How do you experience them?" Emotional implications and suggestions from patients with cancer. *Journal of Cancer Education*.
- Centers for Disease Control and Prevention (2011). Health-Related Quality of Life. Retrieved from <http://www.cdc.gov/hrqol/concept.htm>.
- Centers for Disease Control and Prevention (2013). Fact Sheets - Excessive Alcohol Use and Risks to Men's Health. Retrieved from <http://www.cdc.gov/alcohol/fact-sheets/mens-health.htm>.
- Chou, C., Chen, Y., Chen, C., Chen, J., & Mu, P. (2009). Family experience of waiting for living donor liver transplantation: from parental donor perspective. *Journal Of Clinical Nursing*, 18(12), 1684-1692.
- Christopherson, L. K. (1987). Cardiac transplantation: A psychological perspective. *Circulation*, 75, 57-62.

- Chung, J. (2014). Social networking in online support groups for health: how online social networking benefits patients. *Journal of Health Communication, 19*(6), 639-659.
- Collins, E., White-Williams, C., & Jalowiec, A. (1996). Spouse stressors while awaiting heart transplantation. *Heart & Lung, 25*(1), 4-13.
- Corruble, E., Durrbach, A., Charpentier, B., Lang, P., Amidi, S., Dezamis, A., & ... Falissard, B. (2010). Progressive increase of anxiety and depression in patients waiting for a kidney transplantation. *Behavioral Medicine, 36*(1), 32-36.
- Coyne, J., & Smith, D. (1991). Couples coping with a myocardial infarction: a contextual perspective on wives' distress. *J.Pers.Soc.Psychol, 61*(3), 404-412.
- Covinsky, K., Eng, C., Lui, L., Sands, L., Sehgal, A., Walter, L., Wieland, D., Eleazer, G., Yaffe, K. (2001). Reduced Employment in Caregivers of Frail Elders: Impact of Ethnicity, Patient Clinical Characteristics, and Caregiver Characteristics. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 56*(11): 707–713.
- Creswell, J. (1998) *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, CA: Sage.
- Creswell, J. (2003). *Research design: Qualitative, quantitative, and mixed methods and approaches* (second ed.). Thousand Oaks, CA: Sage.
- Creswell, J. (2013). *Qualitative inquiry and research design. Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.
- Cresp-Gerrard P. (1993). Welcome to our nightmare. An open letter to transplant coordinators. *Med J Aust, 159*(1), 56-57.
- Crockett, S., Gifford, S. (2004). "Eyes wide shut": narratives of women living with hepatitis C in Australia. *Women & Health, 39*(4), 117–137.
- Cutcliffe, J., & Herth, K. (2002). The concept of hope in nursing 1: its origins, background and nature. *British Journal of Nursing, 11*, 834–840.
- Davis, L., Gilliss, C. L., Deshefy-Longhi, T., Chestnutt, D. H., & Molloy, M. (2011). The Nature and Scope of Stressful Spousal Caregiving Relationships. *Journal Of Family Nursing, 17*(2), 224-240.

- Demi, A., Bajeman, R., Moneyhan, L., Sowell, R., Seals, B. (1997). Effects of resources and stressors on burden and depression of family members who provide care to an HIV-infected woman. *Journal of Family Psychology, 11*, 35–48.
- Denzin, N., & Lincoln, Y. (1994). Introduction: Entering the field of qualitative research. In NK Denzin and YS Lincoln (Eds.) *Handbook of Qualitative Research*, p 1-17. Thousand Oaks: Sage Publications.
- Díaz-Domínguez, R., Pérez-Bernal, J., Pérez-San-Gregorio, M., & Martín-Rodríguez, A. (2006). Quality of life in patients with kidney, liver or heart failure during the waiting list period. *Transplantation Proceedings, 38*, 2459-2461.
- Doenges, M., & Moorhouse, M. (2000). *Nurses pocket guide: Diagnoses, interventions and rationales* (7th ed.). Philadelphia: F. A. Davis.
- Domínguez-Cabello, E., Martín-Rodríguez, A., Pérez-San-Gregorio, M., Fernández-Jiménez, E., Sousa-Martin, J., & Bernardos-Rodríguez, A. (2012). Coping Strategies in liver patients as a function of relatives' anxiety level. *Transplant Procurement, 44*, 2616-2618.
- Dominguez, E., Martin, A., & Perez, M. (2010). Influence of relatives' anxious symptomology on the quality of life of pretransplantation hepatic patients. *Transplant Procurement, 42*, 2964.
- Dowling, M. (2007) From Husserl to van Manen: a review of different phenomenological approaches. *International Journal of Nursing Studies, 44*, 1,131-142.
- Drazic, Y., & Caltabiano, M. (2013) Chronic hepatitis B and C: exploring perceived stigma, disease information, and health-related quality of life. *Nursing and Health Sciences, 15* (2), 172-178.
- Dufault, K., & Martocchio, B. (1985). Hope: its spheres and dimensions. *Nursing Clinics of North America, 20*, 379–391.
- Earle, V. (2010). Phenomenology as research method or substantive metaphysics? An overview of phenomenology's uses in nursing. *Nursing Philosophy, 11*(4), 286-296.
- Eatmon, S. (2002). Cancer, caregiving and the family. *Radiat Ther. 11*(2): 133–147.

- Eggenberger, S.K., Meiers, S.J, Krumwiede, N., Bliesmer, M., & Earle, P. (2011). Reintegration within families in the context of chronic illness: A family health promoting process. *Journal of Nursing and Healthcare of Chronic Illness*, 3, 283–292. doi:10.1111/j.1752-9824 .2011.01101.x.
- Eisdorfer, C. (1991). Caregiving: An emerging risk factor for emotional and physical pathology. *Bulletin of the Menninger Clinic*, 238- 248.
- Eun-Ok, I. (2002). A feminist critique of research on women’s work and health. Health Care for women’s work and health.. *Health Care for Women International*, 21, 105-119.
- Fahey, S. (1999). The experience of women with primary biliary cirrhosis: a literature review. *Journal of Advanced Nursing*, 30(2), 506-512.
- Fast, J., Niehaus, L., Eales, J., & Keating, N. (2002a). A profile of Canadian chronic care providers *Final Report Submitted to Human Resources and Development Canada*. Edmonton: Authors.
- Fife, B., & Wright, E. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior*, 41(1), 50–67.
- Forsberg, A., Backman, L., & Moller, A. (2000). Experiencing liver transplantation: a phenomenological approach. *Journal of Advanced Nursing*, 32(2), 327-334.
- Fournier, M., de Ridder, D., & Bensing, J. (2002). Optimism and adaptation to chronic disease: the role of optimism in relation to self-care options of Type 1 diabetes mellitus, rheumatoid arthritis and multiple sclerosis. *Br J Health Psychol*, 7, 409–432.
- Fox, R., & Swayze, P. (1978). *The Courage to Fail*. University of Chicago Press.
- Fox, E. (1997). Predominance of the Curative Model of Medical Care: A Residual Problem. *JAMA*, 278(9):761-763.
- Franklin, S., Ames, B. & King, S. (1994). Acquiring the family eldercare role: Influence of female employment adaptation. *Research on Aging*, 16 (1), 27-42
- Friedman, M. (1992). Family development theory. In M. M. Friedman (Ed.), *Family Nursing: Theory and practice*. (pp. 81-112). Norwalk, CT: Appleton and Lange.
- Gagnon, Y., Levy, A., Iloeke, U., & Briggs, A. (2004). Treatment costs in Canada of health conditions resulting from Hepatitis B infection. *Journal of Clinical Gastroenterology*, 38(10), 179-186.

- Georgetown University Center on an Aging Society (2005). A decade of informal caregiving. Retrieved from <http://ihcrp.georgetown.edu/agingsociety/pdfs/caregivers1-E.pdf>.
- Glazer, K., Emery, C., Frid, D., & Banyasz, R. (2002). Psychological predictors of adherence and outcomes among patients in cardiac rehabilitation. *Journal of Cardiopulmonary Rehabilitation*, 22, 40-46.
- Giorgi, A. (2008). Concerning a serious misunderstanding of the essence of the phenomenological method in psychology, *Journal of Phenomenological Psychology*, 39, 33-58.
- Giovannetti, E., Wolff, J., Frick, K., & Boulton, C. (2009). Construct validity of the work productivity and activity impairment questionnaire across informal caregivers of chronically ill older patients. *Value Health*, 12(6), 1011–1017.
- Given, C., Given, B., & Stommel, M., et al. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairment. *Res Nurs Health*, 15, 271-283.
- Given, L., & Saumure, K. (2008). Trustworthiness. In L. Given (Ed.), *The SAGE encyclopedia of qualitative research methods*. (pp. 896-897). Thousand Oaks, CA: Sage Publications.
- Goetzmann, L., Klaghofer, R., Wagner-Huber, R., Halter, J., Boehler, A., Muellhaupt, B., Schanz, U., & Buddeberg, C. (2007). Psychosocial vulnerability predict psychosocial outcome after an organ transplant: results of a prospective study with lung, liver, and bone marrow patients. *Journal of Psychosomatic Research*, 62, 93-100.
- Golden, J., Conroy, R., Dwyer, A., Golden, D., & Hardouin, J-B. (2006). Illness-related stigma, mood and adjustment to illness in persons with Hepatitis C. *Social Science & Medicine*, 63(12), 3188-3198.
- Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Klotz, L. (1999). Presurgery experiences of prostate cancer patients and their spouses. *Cancer Practice: A Multidisciplinary Journal of Cancer Care*, 7(3), 130–135. doi: 10.1046/j.1523-5394.1999.07308.x.
- Greenberg, S., Stacy, M., & Penzo, J. (2001). Spousal caregiving: In sickness and in health. *Journal of Gerontological Social Work*, 35(4), 69-82.
- Greenfield, T., Midanik, L., & Rogers, J. (2000) 'Effects of Telephone versus Face-to-Face Interview Modes on Reports of Alcohol Consumption', *Addiction*, 95(20): 277–84.

- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1).
- Halm, M., Treat-Jacobson, D., Lindquist, R., & Savik, K. (2007). Caregiver burden and outcomes of caregiving of spouses of patients who undergo coronary artery bypass graft surgery. *Heart & Lung*, 36(3), 170-187.
- Hancock, K., Clayton, J. & Parker, S et al. (2007). Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliative Medicine*, 21, 507-517.
- Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a Fundamental Cause of Population Health Inequalities. *American Journal Of Public Health*, 103(5), 813-821. doi:10.2105/AJPH.2012.301069.
- Hagedoorn, M., Buunk, B. P., Kuijer, R. G., Wobbes, T., & Sanderman, R. (2000). Couples dealing with cancer: Role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology*, 9, 232–242.
- Haugh, K., & Salyer, J. (2007). Needs of patients and families during the wait for a donor heart. *Heart & Lung*, 36(5), 319-329.
- Heidegger, M. (1962). *Being and time*. New York: Harper & Row.
- Heidegger, M. (1979). *Sein und Zeit*. 15th ed. Tubingen: Max Niemayer Verlag.
- Heidegger, M. (2005). *Introduction to Phenomenological Research* (D, Dahlstorm, Trans) Bloomington: Indiana University Press.
- Helland, M. & Winston, B. (2005). Towards a Deeper Understanding of Hope and Leadership. *Journal of Leadership and Organizational Studies*, 12(2). 42-54.
- Hofmann, J., Wenger, N., & Davis, R., et al. (1997). Patient preferences for communication with physicians about end-of-life decisions. SUPPORT Investigators. Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment. *Ann Intern Med*, 127, 1-12.
- Husserl, E. (1962). *Ideas : General Introduction to Pure Phenomenology*, Translated by W. R. Boyce Gibson. London, New York: Collier, Macmillan.
- Husserl, E. (1975). *The Paris Lectures* (P. Koestenbaum, Trans). The Hague: Martinus Hijhoff.
- Husserl, E. (1982) *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy: First book*. (trans F. Kersten). Dordrecht: Kluwer. (Original work published 1913).



- Hwang, H. (1996). Patient and family adjustment to heart transplantation. *Progress in Cardiovascular Nursing*, 11(2), 16-18, 39.
- Ingram, D., & Hutchinson, S. (1999). HIV-positive Mothers and Stigma. *Health Care Women International*, 20(1), 93-103.
- Ivarsson, B., Ekmeahag, B., & Sjoberg, T. (2011). Recently accepted for the waiting list for heart or lung transplantation – patients' experiences of information and support. *Clinical Transplantation* 25, E664–E671.
- Ivarsson, B., Ekmeahag, B., & Sjöberg, T. (2012). Heart or lung transplanted patients' retrospective views on information and support while waiting for transplantation. *Journal Of Clinical Nursing*, 22(11/12), 1620-1628. doi:10.1111/j.1365-2702.2012.04284.x.
- James, N., Daniels, H., Rahman, R., McConkey, C., Derry, J., Young, A. (2007). A study of information seeking by cancer patients and their carers. *Clin Oncol*, 19(5), 356–362.
- Jameton, A. (1984). *Nursing practice: The ethical issues*. Englewood Cliffs, NJ: Prentice-Hall.
- Johnson C., & Hathaway D. (1996) The lived experience of end stage liver failure and liver transplantation. *Journal of Transplant Coordinators* 6, 131-133.
- Jones, L., & Egan, M. (2000). The transplant experience of liver recipients: Ethical issues and practice implications. *Social Work Health Care*, 31(2), 65-88.
- Jonsen, E., Athlin, E., & Suhr, O. (1998). Familial amyloidotic patients' experience of the disease and of liver transplantation. *Journal Of Advanced Nursing*, 27(1), 52-58. doi:http://dx.doi.org/10.1046/j.1365-2648.1998.00503.x.
- Keating, N., Fast, J., Fredrick, M., Cranswick, K., & Perrier, C. (1999). *Eldercare in Canada: Context, content and consequences*. Ottawa: Statistics Canada.
- Kennedy Sheldon, L., Hilaire, D., & Berry, D. L. (2011). Provider Verbal Responses to Patient Distress Cues During Ambulatory Oncology Visits. *Oncology Nursing Forum*, 38(3), 369-375.
- Kittay, E. (195) Taking dependency seriously: The family and medical leave act considered in light of the social organization of dependency work and gender equality. *Hypatia*. 10(1):8-29.

- Kleinman, A.M. (1975). *Explanatory models in health care relationships, in Health of the Family* (National Council for International Health Symp) Washington, D.C., NCIH, 159—172.
- Kleinman, A. (2006). Culture, Illness and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research. *Focus, 4*: 140-149.
- Klemm, P., Hayes, E., Diefenbeck, C., & Milcarek, B. (2014). Online Support for Employed Informal Caregivers: Psychosocial Outcomes. *CIN: Computers, Informatics, Nursing, 32*(1), 10-20.
- Klitzman, R. (2007). "Patient-time", "doctor-time", and "institution-time": Perceptions and definitions of time among physicians who become patients. *Patient Education and Counselling, 66*:147-155.
- Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist, 37*:218-232.
- Kramer, B., & Lambert, J. (1999). Caregiving as a life course transition among older husbands: A prospective study. *The Gerontologist, 39*(6), 658-667
- Kurz, J. (2002). Vulnerability of Well Spouses Involved in Lung Transplantation. *Journal of Family Nursing, 8*, 353.
- Kurz, J. & Cavanaugh, J. (2001). Stressors and coping strategies used by well spouses of lung transplant candidates. *Families, Systems & Health, 19*.181-197.
- Langer, S. (2003). Mood disturbance in the cancer setting: effects of gender and patient/spouse role. *Seminars in Clinical Neuropsychiatry 8*, 276-285.
- Larsson, M., Hedelin, B., Athlin, E. (2007). Needing a hand to hold: Lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. *Cancer Nursing, 30*(4):324-334.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lebel, S. et al., (2003). Waiting for a breast biopsy. Psychological consequences and coping strategies. *Journal of Psychomatic Research, 55*(4): 437-443.
- Leung, K., Silvius, J., Pimlott, N., Dalziel, W., Drummond, N. (2009). Why health expectations and hopes are different: the development of a conceptual model. *Health Expectations, 12*(4): 347-360.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

- Livneh, H. (2000). Psychosocial adaptation to cancer: The role of coping strategies. *Journal of Rehabilitation*, 66(2), 40-49.
- Long, J., Jahnle, E., Richardson, D., Loewenstein, G., & Volpp, K. (2012). Peer mentoring and financial incentives to improve glucose control in African American veterans: a randomized trial. *Annals Of Internal Medicine*, 156(6), 416-424.
- Lopez-Navas, A., Rios, A., Riquelme, A., Martinez-Alarcon, L., Miras, M., Ramirez, P., & Parilla, P. (2010). Coping Styles of Patients on the Liver Transplant Waiting List. *Transplantation Proceedings*, 42, 3149–3152.
- Lopez, K., & Willis, D. (2004). Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qualitative Health Research*, 14(5), 726-735.
- Lumby, J. (1997). Liver transplantation: The life/death paradox. *International Journal of Nursing Practice*, 3, 231-238.
- Macdonald, K. (2006). Living in limbo - patients with cystic fibrosis waiting for transplant. *British Journal Of Nursing*, 15(10), 566.
- Mauss, M. (1958). *The Gift* (trans. W. D. Halls). New York: W. W. Norton.
- Mays, N. & Pope, C. (1995). Qualitative Research: Rigour and Qualitative Research. *BMJ*. 311(6997), 109-112.
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2009). Husserl and Heidegger: Exploring the disparity. *International Journal of Nursing Practice*, 15, 7-15.
- McCormick, K. (2002). A concept analysis of uncertainty in illness. *Journal of Nursing Scholarship*, 34(2), 127-131.
- McCreddie, M., Lyons, I., Horsburgh, D., Miller, M., & Frew, J. (2011). The Isolating and Insulating Effects of Hepatitis C A Substantive Grounded Theory. *Gastroenterology nursing*, 34(1), 49-59doi: 10.1097/SGA.0b013e31820b2254.
- McCurry, A. & Thomas, S. (2002). Spouses' Experiences in Heart Transplantation. *Western Journal of Nursing Research*, 24(2), 180-194.
- McGoldrick, M. (1998). *Re-visioning family theory: Race, culture and gender in clinical practice*. New York: Guilford Press.

- Mendes, A., & Bouso, R. (2009). Not being able to live like before: the family dynamics during the experience of pediatric liver transplantation. *Rev Lat Am Enferm*, 17(1),74-80.
- Mishel, M. (1981) The measurement of uncertainty in illness. *Nursing Research* 30, 258–263.
- Mishel, M. (1984) Perceived uncertainty and stress in illness. *Research in Nursing & Health* 7, 163–171.
- Mishel, M. (1988). Uncertainty in Illness. *Journal of Nursing Scholarship*, 20(4), 225-232.
- Mishel, M. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, 17, 269-294.
- Mishel, M., & Murdaugh, C. (1987). Family adjustment to heart transplantation: Redesigning the dream. *Nursing Research*, 36, 332-338.
- Mongoven, A. (2003) Sharing our body and blood: organ donation and feminist critiques of sacrifice. *Journal of Medicine and Philosophy*, 28, 89-114.
- Moore, G., Hawley, D., & Bradley, P. (2008) Hepatitis C: studying stigma. *Gastroenterology Nursing*, 31(5), 346–52. doi: 10.1097/01.SGA.0000338279.40412.96.
- Moran, A., Scott, A., & Darbyshire, P. (2011). Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. *Journal Of Advanced Nursing*, 67(3), 501-509.
- Moran, D. (2000) *Introduction to phenomenology*. London: Routledge.
- Morse, J. & Field, P. (1995) *Qualitative Research Methods for Health Professionals*.
- Morse, J. M. (1991a). On funding qualitative proposals [Editorial]. *Qualitative Health Research*, 192, 147-151.
- Morse, J. (2000). Determining sample size. *Qualitative Health Research*, 10(1), 3-5.
- Morse, J., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal Of Qualitative Methods*, 1(2), 1-19.
- Mulcahy, C., Parry, D., Glover, T. (2010). The "patient patient": the trauma of waiting and the power of resistance for people living with cancer. *Qualitative Health Research*, 20(8):1062-1075.

- Multi Organ Transplant Program (2013). 2012 Annual Report. Retrieved from <http://www.motphalifax.net/Reports.aspx>.
- Murphy F., Trevitt R., Chamney M., & McCann M. (2011). Patient health and well-being while waiting for renal transplantation: Part I. *Journal of Renal Care*, 37(4), 224–231.
- Naef, R., & Bournes, D. (2009). The lived experience of waiting: a Parse method study. *Nursing Science Quarterly*, 22(2), 141-153.
- Nathaniel, A.K. (2004). A grounded theory of moral reckoning in nursing. *The Grounded Theory Review*, 4(1). 43-58.
- Nijboer, C., Tempelaar, R., Sanderman, R. et al. (1998). Cancer and caregiving: The impact on the caregiver's health. *Psychooncology*, 7:3-13.
- O'Carroll, R., Couston, M., Cossar, J., Masterton, G., & Hayes, P. (2003). Psychological outcome and quality of life following liver transplantation: a prospective, national, single-center study. *Liver Transplant*, 9(7), 712-720.
- Oldbrisch, M., Benedict, S., Ashe, K., & Levenson, J. (2002). Psychological Assessment and Care of Organ Transplant Patients. *Journal of Consulting and Clinical Psychology*. 70(3), 771-783.
- Ong, A., Edwards, L., & Bergeman, C. (2006). Hope as a source of resilience in later adulthood. *Personality and Individual Differences*, 41, 1263–1273.
- Oxford Dictionary (2014). Conundrum. Retrieved from <http://www.oxforddictionaries.com/definition/english/conundrum>
- Oxford Dictionary (2014). Hope. Retrieved from <http://www.oxforddictionaries.com/definition/english/hope>
- Oxford Dictionary (2013). Waiting. Retrieved from <http://www.oxforddictionaries.com/definition/english/wait>
- Pare, Ambrose & Packard, Francis Randolph. (1921) *Life and times of Ambrose Paré* [1510-1590]. New York: New York. P. B. Hoeber.
- Pelletier, J. (2008). The experience of waiting for a transplant for the transplant candidate and spouse. *Southern Online Journal of Nursing Research*, (8), 2.
- Pineault, P. (2007). Breast cancer screening: women's experiences of waiting for further testing. *Oncology Nursing Forum* 34(4), 847-853.

- Pinnegar, S., & Dayes, J. (2007). Locating narrative inquiry historically: Thematic in the turn to narrative. In D. J. Clandinin (Ed.) *Handbook of narrative inquiry: Mapping a methodology* (pp.3-34). Thousand Oaks, CA: Sage.
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*, 250–267.
- Plante-Bordeneuve, V. & Said, G. (2011). Familial amyloid polyneuropathy. *Lancet Neurology, 10*, 1086-1097.
- Rajacich, D. (2007). *The meaning of waiting for women along the breast cancer journey*. Hamilton, ON, McMaster University; 2007.
- Rasmussen, H., Scheier, M., & Greenhouse, J.(2009). Optimism and physical health: A meta-analytic review. *Annals of Behavioral Medicine, 37*, 239-256. doi: 10.1007/s12160-009-9111-x.
- Reed, G., Kemeny, M., Taylor, S., & Visscher, B. (1999). Negative HIV-specific expectancies and AIDS-related bereavement as predictors of symptom onset in asymptomatic HIV-positive gay men. *Health Psychol, 18*, 354–363.
- Reid, L. (2014) Introduction. In Sabo, B., McLeod, D., Reid, L., Hastings, T., Wells, C., Snelgrove-Clarke, E., Cooper, E., Couban, S., Sullivan, V., Howes, J., & Maginley, D. (2014). *HSCT Survivor & Caregiver Experiences: A Learning Module*. Retrieved from [www.hsctpatientsandcaregivers.ca](http://www.hsctpatientsandcaregivers.ca).
- Richmond, J., Dunning, P., & Desmond, P. (2004). Hepatitis C: A medical and social diagnosis. *Australian Nursing Journal, 12*(1), 23–25.
- Rickman, J. (2001). Waiting for a transplant. *British Medical Journal, 322*, 293-294.
- Riess-Sherwood, P., Given, B. & Given, C. (2002). Who Cares for the Caregiver: Strategies to Provide Support. *Home Health Care Management and Practice, 14*, 2, 110-121.
- Robertson, G. (1999). Individuals' perception of their quality of life following a liver transplant: An exploratory study. *Journal of Advanced Nursing, 30*: 497–505.
- Robertson, C. (2005). Organ advertising: desperate patients solicit volunteers. *Journal of Law, Medicine and Ethics, 33*(1), 170-174.
- Robinson, J, & Turner, J. (2003 ). Impersonal, interpersonal, and hyperpersonal social support: Cancer and older adults. *Health Communication, 15*, 227-234.

- Robson, N., Razack, A., & Dublin, N. (2010). Review paper: Organ transplants: ethics, social, and religious issues in a Multicultural society. *Asia Pac J Public Health, 22*(3):271-8
- Rolland, J. S. (1994). Families, illness, and disability: An integrative treatment model. New York: Basic Books.
- Rolland, J. (1994). Sickness and in Health: The Impact of Illness on Couples' Relationships. *Journal of Marital and Family Therapy, 20*(4). 327-347.
- Rosland, A., Heisler, M., Piette, J. (2012). The impact of family behaviors and communication patterns on chronic illness outcomes: a systematic review. *Journal Of Behavioral Medicine, 35*(2), 221-239.
- Sabo, B. (2013). Waiting and Liminality: A Phenomenon of Spousal Caregiving? *Cancer Nursing*. In press.
- Sabo, B., McLeod, D., & Couban, S. (2013). The Experience of Caring for a Spous Undergoing Hematopoietic Stem Cell Transplantation: Opening Pandora's Box. *Cancer Nursing, 36*(1), 29-40. doi:10.1097/NCC.0b013e31824fe223.
- Sandelowski, M. (1995). Focus on qualitative methods: Sample sizes in qualitative research. *Research in Nursing & Health, 18*, 179-183.
- Sander-Staudt. (2014). Care Ethics. Internet Encyclopedia of Philosophy. Retrieved from <http://www.iep.utm.edu/care-eth/#SSH1cv>.
- Sanner, M. (2003). Transplant recipients' conceptions of three key phenomena in transplantation: the organ donation, the organ donor, and the organ transplant. *Clinical Transplantation, 17*(4), 391-400. doi:10.1034/j.1399-0012.2003.00065.x.
- Saxe-Braithwaite, M., & Chapman, J. (1992). Life on hold: the experience of the support person involved in a lung transplant program. *The Canadian Journal of Nursing Research, 24*(3):69-80.
- Scanlon, C. (1989). Creating a vision of hope: The challenge of palliative care. *Oncology Nurs Forum, 16*, 491-49.
- Scharlach, A., & Boyd, S. (1989). Caregiving and employment: Results of an employment survey. *The Gerontologist, 29* (3), 383-387.
- Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality. *Journal of the American Medical Association, 282*, 2215-2219.

- Schulz, R., & Martire, L. (2004). Family Caregiving of Persons with Dementia: Prevalence, Health Effects, and Support Strategies. *Am J Geriatr Psychiatry, 12*, 240-249.
- Siminoff, L. & Chillag, K. (1999). The fallacy of the "Gift of life". *Hastings Center Report, 29*(6):34-41.
- Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., et al. (1991). The will and the ways: Development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology, 60*, 570–585.
- Sogolow, E., Lasker, J., Sharim, R., Weinrieb, R., & Sass, D. (2010). Stigma and liver disease. *Illness, Crisis, & Loss, 18*(3), 229-255.
- Spaid, W. & Barusch, A. (1994). Emotional closeness and caregiver burden in the marital relationship. *Journal of Gerontological Social Work, 21* (3/4). 197-211.
- Speziale, H. J. S., & Carpenter, D. R. (2007). *Qualitative research in nursing: Advancing the humanistic imperative* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Stewart, B., Mikocka-Walus, A, Harley, H., & Andrews, J. (2012). Help-seeking and coping with the psychosocial burden of chronic hepatitis C: A qualitative study of patient, hepatologist, and counsellor perspectives. *International Journal Of Nursing Studies, 49*(5), 560-569.  
doi:10.1016/j.ijnurstu.2011.11.004.
- Stilley, C., DiMartini, A., Tarter, R., DeVera, M., Sereika, S., Dew, M., & ... Flynn, W. (2010). Liver transplant recipients: individual, social, and environmental resources. *Progress In Transplantation, 20*(1), 68-74.
- Sturges, J., & Hanrahan, K. (2004). Comparing telephone and face-to-face qualitative interviewing: a research note. *Qualitative Research, 4*(1), 107-118.
- Suszycki, L.H. (1988). Psychosocial aspects of heart transplantation. *Social Work, 33*, 205-209.
- Taylor, D., Kuchibhatla, M., Ostbye, T., Plassman, B., & Clipp, E. (2008). The effect of spousal caregiving and bereavement on depressive symptoms. *Aging and Mental Health, 12*(1), 100-107.
- Telles-Correia, D., Barbosa, A., Mega, I., & Monteiro, E. (2009). Importance of depression and active coping in liver transplant candidates' quality of life. *Progress In Transplantation, 19*(1), 85-89.



- Taylor, S., & Brown, J. (1988). Illusion and well-being: A social psychological perspective on mental health". *Psychological Bulletin*, *103*(2), 193–210.
- Thornburg, P. (2002). Waiting as experienced by women hospitalized during the antepartum period. *American Journal of Maternal/ Child Nursing*, *27*, 245-248.
- Trimm, D. (1997). Spousal coping during the surgical wait. *Journal of Perianesthesia*. *12* (3), 141-1 51.
- Tronto, J. (1993). *Moral boundaries: A political argument for an ethic of care*. New York: Routledge.
- Trost, S. E. (2005). Protective buffering among couples coping with heart disease: Behavior, intentions, and psychological distress. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, *65*, (9-B), 4855.
- Thorne, S. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.
- Uitterhoeve, R., de Leeuw, J., Bensing, J., Heaven, C., Borm, G., deMulder, P., & van Achetrberg, T. (2007). Cue-responding behaviors of oncology nurses in video-simulated interviews. *Journal of Advanced Nursing*, *61*, 71–80.
- van Manen, M. (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. New York: State University of New York Press. Thousand Oaks, CA: Sage.
- van Manen, M. (2001). *Researching lived experience: Human science for an action sensitive pedagogy* (Original work published 1990). Toronto, ON: The Althouse Press.
- Veldt, B., Heathcote, J., Wedemeyer, H., Reichen, J., Hofmann, P., Zeuzem, S., . . . & Janssen, H. (2007). Sustained Virologica Response and Clinical outcomes in Patients with Chronic Hepatitis C and Advanced Fibrosis. *Ann Intern Med*, *147*(10), 677-684.
- Wainwright, S. (1995). The transformational experience of liver transplantation. *J Adv Nurs*, *22*(6), 1068-76.
- Wainwright, S. (1997). Transcending chronic liver disease: a qualitative study. *Journal Of Clinical Nursing*, *6*(1), 43-53. doi:10.1111/j.1365-2702.1997.tb00282.x.

- Wait. (2013). Oxford Dictionary Online. Retrieved from <http://www.oxforddictionaries.com/definition/english/wait>.
- Walther, J., & Boyd, S. (2002). Attraction to computer-mediated social support. In C. A. Lin & D. Atkin (Eds.), *Communication technology and society: Audience adoption and uses* (153–188). Cresskill, NJ: Hampton Press.
- Walsh, F. (1983). The timing of symptoms and critical events in the family life cycle. In H. Liddle (Ed.), *Clinical implications of the family life cycle* (pp. 120-133). Rockville, MD: Aspen Systems.
- Walsh, F. (1996). The Concept of Family Resilience: Crisis and Challenge. *Family Process*, 35(3), 261-281.
- Walsh, F. (2003). Family resilience: a framework for clinical practice. *Family Process*, 42(1), 1-18.
- Walsh, F. (2006). *Strengthening Family Resilience*. 2<sup>nd</sup> ed. New York, New York: The Guilford Press.
- Webster, G., & Baylis, F. (2000). Moral residue. In S. B. Rubin & L. Zoloth, *Margin of error: The ethics of mistakes in the practice of medicine* (pp. 217-232). Hagerstown, M.D: University Publishing Group.
- Weems, J., & Patterson, E. T. (1989). Coping with uncertainty and ambivalence while awaiting a cadaveric renal transplant. *ANNA Journal*, 16(1), 27-31.
- Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology*, 39, 806-820.
- Williams, M. (1991). *Life on hold: A theory of spouse response to the waiting period prior to heart transplantation*. Unpublished doctoral dissertation, University of Arizona.
- Wittmann, M., Vollmer, T., Schweiger, C., Hiddemann, W. (2006). The relation between the experience of time and psychological distress in patients with hematological malignancies. *Palliative and Supportive Care*, 4(4):357-363.
- Wright, L. & Bell, J. (2009) *Beliefs and Illness: A Model for Healing*. 4th Floor Press, Calgary, Canada.
- Yeh, S., & Chen, P. (2010). Gender disparity of hepatocellular carcinoma: the roles of sex hormones. *Oncology*, 78: 172-179.
- Yelle, M., Stevens, P., & Lanuza, D. (2013). Waiting Narratives of Lung Transplant Candidates. *Nursing Research and Practice*, 2013. doi:10.1155/2013/794698.

- Yin, R. (2009). *Case study research: design and methods*. 2nd ed. Thousand Oaks.
- Youngner, S. (2003) Some must die. *Zygon* 38, 705–724.
- Zelikovsky, N., Schast, A., Jean-Francois, D. (2007). Parent Stress and Coping: Waiting for a Child to Receive a Kidney Transplant. *J of Clin Psychol Med Settings*, 14, 320-329.
- Zickmund, S., Ho, E. Y., Masuda, M., Ippolito, L., & LaBrecque, D. R. (2003). “They treated me like a leper”: Stigmatization and the quality of life of patients with hepatitis C. *Journal of General Internal Medicine*, 18(10), 835–844.
- Zink, S., & Wetlieb, S. (2004). Forced Altruism is not Altruism. *American Journal of Bioethics*, 4(4), 29-31.

## **Appendix A Letter of Invitation to Participate From Transplant Program**

**Patient Name**  
**Address**  
**City / Town & Province**  
**Postal Code**

**Dear \_\_\_\_\_,**

The staff physicians and nurses of the Pre-Liver Transplant Clinic at Capital Health have agreed to assist a nursing colleague at the QEII Health Sciences Centre who is completing her Masters of Nursing at Dalhousie University. This study involves talking to patients and their caregivers who are currently waiting for a liver transplant in Atlantic Canada. The study is called “Waiting for a liver transplant: An exploration of the lived experience of patients and their caregivers in Atlantic Canada”. You may be interested in participating in this research study, as it would involve you and your caregiver talking about your experiences of waiting for a liver transplant.

Participation in this study will involve being interviewed (in person or by telephone) by the nurse, Bridget Pierce and answering a short demographic form. Interviews may last from 60 to 90 minutes in length, and you and your self-identified caregiver will be interviewed separately. The interview will explore your experiences while you / the person you care for are waiting for a liver transplant.

Your decision to participate or not participate will not affect the care you receive at Capital Health. Your physicians and nurses caring for you will not know whether or not you have participated in the study. Your participation is completely voluntary. You may choose to withdraw from the study at any time after agreeing to participate. If you choose to participate you will receive \$40 to cover your time, a meal and parking.

If you are interested in learning more about this research study or have questions, please contact the study investigator Bridget Pierce by telephone at (902) 478-4440 or by email at [bridgetpierce@dal.ca](mailto:bridgetpierce@dal.ca).

Thank you,

Dr. Kevork M. Peltekian  
Medical Director, Liver Team, Atlantic Multi-Organ Transplantation Program



Capital Health

## Appendix B Study Advertisement



### **Are you (or the person you care for) waiting for a liver transplant?**

**Why:** Current research literature has identified the period spent waiting for a liver transplant to be filled with many psychological, emotional and physical experiences for both the patient and their caregiver(s). As a result, I am conducting a research study exploring how the patient and their caregiver in Atlantic Canada experience waiting for a liver transplant.

**Who:** You may be eligible for participation in this research study if you:

- are currently listed on the liver transplant wait list in Atlantic Canada
- have a self-identified caregiver (friend, family, spouse etc.)
- are 18 years or older
- speak English
- travel to Halifax for your 3-month follow-up appointments

**What:** Each participant (both the patient and family caregiver) will be asked to complete a face-to-face (or telephone) interview with the principal investigator. The patient and their family caregiver will be interviewed separately.

Thank you for your consideration, if you would like more information or would like to participate please contact me:

**Bridget Pierce** (RN, BScN, MN student) - (902) 478-4440 or  
Bridgetpierce@dal.ca

**Thesis Supervisor:** Dr. Brenda Sabo - (902) 494-2131 or  
Brenda.Sabo@dal.ca

## **Appendix C Informed Consent**

**STUDY TITLE:** Waiting for a Liver Transplant: An exploration of the lived experience of patients and their caregivers in Atlantic Canada.

**PRINCIPAL INVESTIGATOR** Bridget Pierce  
Dalhousie University Masters of Nursing Student  
Bridgetpierce@dal.ca  
902-478-4440

### **1. Introduction**

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- Discuss the study with you
- Answer your questions
- Keep confidential any information which could identify you personally
- Be available during the study to deal with problems and answer questions

We do not know if taking part in this study will help you. You may feel better. On the other hand it might not help you at all. It might even make you feel worse. We cannot always predict these things. We will always give you the best possible care no matter what happens.

If you decide not to take part or if you leave the study early, your usual health care will not be affected.

### **2. Why Is This Study Being Done?**

I am a student in the Master of Nursing program at Dalhousie University in Halifax, Nova Scotia. I am completing a research study for my Masters thesis that explores the experience of waiting for a liver transplant in Atlantic Canada for the patient and their caregiver.

The available literature on waiting for a liver transplant has identified that this process is a complex one, where patients, their caregivers and their family members experience many different psychological, emotional, mental and physical feelings. The literature has identified that this time is filled with a high level of uncertainty, and that this can be helped with further information from health care providers. The purpose of this study is to understand how patients and their caregivers live out and assign meaning to the experience of waiting for a liver transplant.

### **3. Why Am I Being Asked To Join This Study?**

You have been asked to join the study as you or your partner/person you care for/spouse/family members are actively listed on the liver transplant wait list in Atlantic Canada. There is a limited amount of research on the experience of waiting for a transplant, particularly exploring the wait for a liver transplant. This limited amount of research gives reason for this study to be done that explores this period of waiting for a liver transplant.

### **4. How Long Will I Be In The Study?**

This study will involve one face-to-face (or telephone) interview that will last between 60 to 90 minutes. After initial data analysis, you will be contacted for a brief telephone conversation to clarify findings of the study. After your interview and this telephone call your participation in the study will be complete.

### **5. How Many People Will Take Part In This Study?**

We are hoping to recruit 6 people (3 patients, 3 caregivers) to take part in this study. The study is taking place in Nova Scotia, but participants who live outside of Halifax Regional Municipality may participate as well as individuals living in New Brunswick or Prince Edward Island.

### **6. How Is The Study Being Done? What Will Happen if I Take Part In This Study?**

Participating in the study will involve one face-to-face (or telephone) interview that will last between 60 and 90 minutes. As the principal investigator, I will interview you. I will make every effort to schedule this interview while you or your caregiver are in Halifax for your or the person you care for pre-liver transplant clinic appointment. The interview will be held in a place that is convenient for you, such as a room within the VG Hospital, or at a convenient non-hospital location. You are free to leave or stop your participation in the study at any time. Stopping your participation will not have any affect on your or the person your care for future treatment(s). The interview will be recorded on a voice recorder and then typed into

text. You will be provided with a copy of the typed interview to review. You may change or ask to have certain parts of your story removed. The interviews will be read and listened to, to identify any themes, patterns, similarities and differences across participants' interviews about the experience and meaning of waiting for a liver transplant.

## **7. Are There Risks To The Study?**

There are risks with this, or any study. I want to make sure that if you decide to try the study, you have had a chance to think about the risks carefully. The risk of this study is thought to be minimal.

The interview may be upsetting, given the sensitive nature of waiting for a liver transplant. Any questions that are too upsetting do not have to be answered, and your participation is completely voluntary. If you are feeling upset during or after the interview, the Multi Organ Transplant Program psychologist is available for you to speak too.

Your participation in this study will in no way impact upon the care you receive from any healthcare providers at the transplant clinic, and they will not know whether or not you have participated in this study.

## **8. What Happens at the End of the Study?**

The research study results will be used for my Master of Nursing thesis. Each participant will be given a copy of my thesis if desired.

## **9. What Are My Responsibilities?**

As a study participant your responsibility is to attend the scheduled interview, follow the directions of the principal investigator, or to withdraw if you no longer wish to participate in the study.

## **10. Can I Be Taken Out Of The Study Without My Consent?**

Yes. You may be taken out of the study at any time, if:

- There is new information that shows that being in this study is not in your best interests.
- You wish to withdraw from the study.
- The Capital Health Research Ethics Board or myself or my Thesis Supervisor (Dr. Sabo) decides to stop the study.



## **11. What About New Information?**

It is possible (but unlikely) that new information may become available while you are in the study that might affect your health, welfare, or willingness to stay in the study. If this happens, you will be informed, in a timely manner, and will be asked whether you wish to continue taking part in the study or not.

## **12. Will It Cost Me Anything?**

### Compensation

You will not be paid to be in this study. You will receive \$40.00 to cover meals, parking and for your time on the day of your interview.

### Research Related Injury

If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the Principal Investigator, the research staff or involved institutions from their legal and professional responsibilities.

## **13. What About My Right To Privacy?**

Protecting your privacy is an important part of this study.

When you sign this consent form you give us permission to:

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

### Access to records

The Principal Investigator and her supervisor (Dr. Sabo) will not be accessing your health records for the purpose of this study.

### Use of records

The Principal Investigator and her supervisor will not be accessing your health records for the purpose of this study. General demographic information will be collected from you. This includes:

- Age range

- Gender
- Diagnosis requiring liver transplantation
- Information from study interviews and questionnaires

Your name and contact information will be kept secure by the Principal Investigator In Halifax, Nova Scotia. It will not be shared with others without your permission. Your name will not appear in anything that is published (research articles, etc) as a result of this study.

Information collected for this study will be kept for a period of 7 years. I will store your information in a locked cabinet in the office of my supervisor, Dr. Brenda Sabo. Information that uses your assigned “fake / study name” will be stored on my password protected computer. Documents that include your real name and your fake/ study name will not be stored together. No research data will be transported outside of the province, and all data will be password encrypted and/or locked. All data (audiotapes, papers) will be transported in a locked briefcase.

You may also be contacted personally by Research Auditors for quality assurance purposes.

#### Your access to records

You may ask to see the information that has been collected about you. If you would like a transcribed copy of your interview, this will be provided to you.

### **14. What if I Want to Quit the Study?**

If you chose to participate and later change your mind, you can say no and stop the research at any time. If you wish to withdraw your consent please inform the Principal Investigator. All data collected up to the date you withdraw your consent will remain in the study records, to be included in study related analyses. A decision to stop being in the study will not affect any care you receive from the transplant program.

### **15. Declaration Of Financial Interest**

The study investigator has no financial interest in completing this study.

### **16. What About Questions Or Problems?**

For future information about the study please call Bridget Pierce at (902) 478-4440 or email me at [bridgetpierce@dal.ca](mailto:bridgetpierce@dal.ca). You may also contact my supervisor, Dr. Brenda Sabo at (902) 494-3121/902-478-6435 or at [brenda.sabo@dal.ca](mailto:brenda.sabo@dal.ca).

### **17. What Are My Rights?**

After you have signed this consent form you will be given a copy.

If you have any questions about your rights as a research participant, contact the **Patient Representative** at **(902) 473-2133**.

*In the next part you will be asked if you agree (consent) to join this study. If the answer is “yes”, you will need to sign the form.*

## 18. Consent Form Signature Page

I have reviewed all of the information in this consent form related to the study called:

Waiting for a Liver Transplant: An exploration of the lived experience of patients and their caregivers in Atlantic Canada

I have been given the opportunity to discuss this study. All of my questions have been answered to my satisfaction.

This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time.

\_\_\_\_\_  
Signature of Participant                      \_\_\_\_\_ Name (Printed)                      \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Year    Month    Day\*

\_\_\_\_\_  
Witness to Participant's  
Signature                      \_\_\_\_\_ Name (Printed)                      \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Year    Month    Day\*

\_\_\_\_\_  
Signature of Investigator                      \_\_\_\_\_ Name (Printed)                      \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Year    Month    Day\*

\_\_\_\_\_  
Signature of Person Conducting  
Consent Discussion                      \_\_\_\_\_ Name (Printed)                      \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Year    Month    Day\*

If the consent discussion has been conducted in a language other than English, please indicate:

\_\_\_\_\_  
Language

\_\_\_\_\_  
Signature of Translator                      \_\_\_\_\_ Name (Printed)                      \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Year    Month    Day\*

*\*Note: Please fill in the dates personally*

**I Will Be Given A Signed Copy Of This Consent Form**

***Thank you for your time and patience!***

## **Appendix D Telephone Consent**

Waiting for a Liver Transplant: An exploration of the lived experience of patients and their caregivers in Atlantic Canada

Telephone Interview Consent Script:

PI: Hello my name is Bridget Pierce and I thank you for agreeing to learn more about my research study. I am a Registered Nurse and I am studying the experience of waiting for a liver transplant for patients and their caregivers in Atlantic Canada as a part of my Masters thesis. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive.

You have been asked to join the study as you or your partner/person you care for/spouse/family members are actively listed on the liver transplant wait list in Atlantic Canada. This study will involve one telephone interview that will last between 60 to 90 minutes. The interview will be audio recorded and then typed into text. After initial data analysis, you will be contacted for a brief telephone conversation to clarify findings of the study. After your interview and this telephone call your participation in the study will be complete. If you choose to participate, you will be one of six participants in the study.

There are risks with this, or any study, however the risk of this study is thought to be minimal. The interview may be upsetting, given the sensitive nature of waiting for a liver transplant. Any questions that are too upsetting do not have to be answered, and your participation is completely voluntary. If you are feeling upset during or after the interview, the Multi Organ Transplant Program psychologist is available for you to speak too.

Your participation in this study will in no way impact upon the care you receive from any healthcare providers at the transplant clinic, and they will not know whether or not you have participated in this study.

Protecting your privacy is an important part of this study. If you choose to verbally consent to this study you give us permission to: Collect information from you, share information with the people conducting the study and share information with the people responsible for protecting your safety. Your health records or medical charts will not be accessed as a part of this study. The care you are provided will in no way be impacted upon, and your health care providers at the transplant program will not know if you participated. Your name and contact information will be kept secure by the Principal Investigator in Halifax, Nova Scotia. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Do you have any questions or concerns about the research study?

PI: [If the participant has no questions, or after all questions have been answered adequately for the participant]: If you have no further questions, do you give your consent to participate in this research study with the ability to withdraw this consent at any time?

## Appendix E Demographic Information Tool

Demographic Information Collection Tool      Pseudonym / Identifier:

---

1. What gender do you identify with?

- Male
- Female

2. How old are you?

- 18-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71+

3. What is your diagnosis leading to requiring a liver transplant?

- Cirrhosis – Alcohol
- Cirrhosis – Other
- Viral Hepatitis
- Hepatocellular Carcinoma
- Autoimmune
- Fatty liver disease
- Other: \_\_\_\_\_

4. How long have you been waiting on the liver transplant wait list?

- Less than 1 month

- 1-3 months
- 3-6 months
- 6-9 months
- 9-12 months
- 12-18 months
- 18 months +



## **Appendix F Interview Guide**

### **Waiting for a Liver Transplant: An exploration of the lived experience of patients and their caregivers in Atlantic Canada**

Interview guide for patient participant:

#### **Examples of potential questions:**

1. When you hear the word, “waiting”, what thoughts immediately come to mind?
2. What has your experience of waiting to receive a liver transplant been like for you? Tell me everything about this experience.
3. What has been the biggest challenge for you as you wait for a liver transplant?
4. What gives you strength to wait? Has this always been your approach in life? If not, how has this changed for you?
5. In thinking about your family, how and in what way do you think this has affected your family?
6. What would be the biggest help for you while you wait

Potential prompts:

How have you experienced this waiting?

What is it like to wait for a liver transplant?

How has this waiting impacted upon your everyday life?

Has your experience of waiting for a liver transplant changed over time?

How do you manage the time spent waiting for a liver transplant?

## **Interview guide for caregiver participant:**

### **Examples of potential questions:**

1. When you hear the word, “waiting”, what thoughts immediately come to mind?
2. What has your experience of waiting for your spouse/family member/friend to receive a liver transplant been like for you? Tell me everything about this experience.
3. What has caregiving been like for you as you support your spouse/family member/friend during this time of waiting?
4. What has been your biggest challenge to date?
5. What gives you strength?
6. What would you do differently if you had to do it over again?
7. What would be the biggest help for you?

### Potential prompts:

How have you experienced this waiting?

What is it like to care for someone who is waiting for a liver transplant?

How has this waiting impacted upon your everyday life?

Has your experience of waiting for \_\_\_\_\_’s liver transplant changed over time?

How do you manage the time spent caring for someone who is waiting for a liver transplant?