

Home is Where the Heart is: The Connection Between Home and the Heart

Transplant Journey

by

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CONNECTION BETWEEN HOME AND THE HEART TRANSPLANT JOURNEY

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DEDICATION

I dedicate this project to Jamie. This project is for you.

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ABSTRACT

Every year more and more Canadians are diagnosed with heart failure. For some who receive this diagnosis, a heart transplant is required. Heart transplants are not performed in every province in Canada; thus, patients and caregivers must relocate to access transplant care. The research question I sought to answer is: How is *home* connected to the heart transplant journey?

The purpose of my study is to learn from the lived experiences of patients and caregivers, as well as through my lived experience as a caregiver who relocated with a patient to access a heart transplant. To explore these various perspectives two methodologies were used.

First autoethnography was used to analyze journal writing which described my experience as a caregiver, who relocated with my husband Jamie, to access a heart transplant. My journals were written during my relocation, which occurred from 2014 to 2017. In total there were 947 journal entries. From my journals, I identified the challenges associated with relocating which include: the stress of finding accommodations, limited finances, a lack of mental health supports, and the challenges associated with being an out of province patient. The supports I found helpful during relocation include my immediate and extended family, and the transplant team. While I did not define *home* in my journals, it was clear to me that, *home* meant Newfoundland, my house in Newfoundland, as well as my parents' house in Newfoundland.

Second narrative analysis was used to explore patient and caregiver perspectives of relocating to access a heart transplant. Nineteen interviews were conducted, and during these interviews patients and caregivers identified the challenges they faced during relocation, the

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supports that made relocation easier, and their definitions of home. The challenges patients and caregivers faced were the same as the ones I had identified in my journals - the stress of finding somewhere to live, financial stress, a lack of mental health support, and the challenges associated with being an out of province patient. Patients and caregivers also identified three things that helped them during their transplant journey – family, other patients and caregivers and the transplant team. When asked to define home, patients and caregivers used words such as family, community, warmth, comfort, safety and belonging.

When I combined both the autoethnography and narrative analysis I was able to ascertain that *home* is not a geographical location or physical space. Home is defined by people, and how these people make us feel, thus home is connected to the transplant journey. With this connection in mind, this research aims to create an understanding of the unique challenges that patients and caregivers who relocate face, and that supports be created to meet the needs of this population.

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PROLOGUE

I don't know what's wrong with me. I was so crooked^{}, mad, and upset.*

Everything was getting on my nerves[†]. I want to go home but I don't know If I'm able to leave Jamie. I would never forgive myself if something happened to him and I was in Newfoundland. September 14, 2015.

Newfoundland is one of the most unique places on earth. It is an island in the middle of the Atlantic Ocean, with weather so unpredictable, you can experience all four seasons in one day. Its landscapes will take your breath away, and once you meet someone from Newfoundland, they are your friend for life. It has a small-town vibe, where everyone knows everyone, and you will find a connection no matter where you go. There is a saying to the effect of 'How do you spot a Newfoundlander in heaven? They are the only person who wants to go home'. For whatever reason Newfoundland has a grasp on its people, making them want to go home no matter where they are in the world. I am very lucky to say that Newfoundland is my home.

Despite all of Newfoundland's beauty and comradery, I write this dissertation from a very different home. A place where you walk out your door and hear languages from every part of the world. A city that never really sleeps and has a population that is six times

* Expression from Newfoundland meaning grumpy, cranky, grouchy

† Expression from Newfoundland meaning the person is feeling annoyed, irritated, or pestered

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larger than the entire province of Newfoundland. I write this dissertation from my second home – Toronto. A city I entered as a guest, and was hosted by doctors and nurses, only to return to make it my second home. Given that this research focuses on the concept of *home*, it seems only fitting and appropriate to acknowledge the lands of my two homes – where I grew up, and where I currently reside.

As a white settler of Irish ancestry, I grew up in Newfoundland, the ancestral homelands of the Mi'kmaq and Beothuk. I also want to recognize that the Inuit of Nunatsiavut and NunatuKavut and the Innu of Nitassinan, are the original people of Labrador.

I now reside in Toronto, where for thousands of years, it has been the home and traditional land of the Huron-Wendat, the Seneca, and the Mississaugas of the Credit. Today, this place in the Dish with One Spoon, is still home to many Indigenous people from across Turtle Island, and I am grateful to have the opportunity to work on this land. The protocols of an individual's own Nation are not forgotten; however, it is one's responsibility to learn and follow protocols of the hosts (Kolezar-Green, 2018). So, while I work and live in Toronto, I am still influenced by my Newfoundland roots. I am cognizant that Newfoundland will always be 'home', yet each and every day I learn more about what is needed to make Toronto my new home, and embrace the cultures, values, and traditions of the place where I currently reside.

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Today we met another couple from [Newfoundland] ... After meeting them, I started to think about how much money it must cost the Government of Newfoundland to send people out of province for treatment. I think of all the people we've met, and that is just at this hospital on Jamie's floor. How many more are there in other hospitals? Other provinces?... This started to get me thinking that this could be a very good research study. Possible Ph.D.? March 27, 2015

My idea for this project came about in 2015. I had been living in Toronto for about six months with my husband Jamie, who needed a heart transplant, which was not available in our home province. Moving to Toronto was difficult for Jamie and I, as we felt as if we had been plucked from our home and dropped into a foreign place, not by choice but by necessity. Relocation turned our lives upside down. We left our house, family, community, and jobs behind and attempted to set up a temporary home while dealing with a serious illness.

Once in Toronto, we began to meet others like us who had also left their homes and relocated to receive treatment. During our time in Toronto, I began documenting my experience in journals. At the time, I did not know how I would eventually use my journals, or that they would become part of my doctoral studies, but as time has passed and I reflect on all that has transpired, I found the seed of my thesis in my journals.

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Jamie and I struggled with relocation, and I wondered if these challenges were unique to us. As we began to meet more and more patients and caregivers, we learned that they too had struggled with relocation and longed for home. I began to wonder: What is *home*? How is the concept of *home* impacted by the relocation experience? Speaking with patients and caregivers who had gone through similar experiences was important to me. It was critical, not just to capture Jamie's and my relocation experience, but to capture the experience of others who had relocated to access transplant care, as a means to better understand the shared experience of this population. I began to realize that while the situation I found myself in was not something I asked for nor wanted, it gave me a unique perspective that I could use to help others, to ensure patients and caregivers who relocate are supported, and to create change in the health care system. As more and more individuals in Canada are diagnosed each year with heart failure, and the treatment required to meet their needs is not available in all provinces, it is inevitable that patients and caregivers must relocate in order to survive.

This research is important to me on a personal level, as it allows me to make sense of my experience, to process what happened, to gain perspective, and to deal with a tremendous loss. Carolyn Ellis shares her thoughts on how autoethnography not only helps others, but also helps the writer; "You come to understand yourself in deeper ways. And with understanding yourself, comes understanding others. Autoethnography provides an avenue for doing something meaningful for yourself and the world" (Ellis, 1999, p. 672).

While the initial goal of my research was to learn how *home* is connected to the transplant journey, I realized that *home* is not always defined by geography or physical place, but

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that we can make a *home* wherever we may be, with whomever we are with, and the feelings and emotions we, and others around us create.

As I write the final pieces of my dissertation, I cannot help but reflect on my *home* – Newfoundland, while also realizing that Toronto is also my *home*. Of course, I miss living by the ocean, seeing my parents and sister daily, and hearing the familiar Newfoundland accent. While I do miss these aspects of *home*, I get great satisfaction from being in a position to host other guests who are just relocating to Toronto.

This journey began because I had to leave home, followed by homesickness and a longing to return. There were bumps, ups and downs, and challenges along the way, but it led me to realize that *home* is where we make it. It does not have to be a physical place. It is about people, community, and how we feel. It is about love, kindness, support, and the need and willingness to help each other. Working with transplant patients and caregivers reminds me each and every day of the courage, strength, and determination of the human spirit.

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GLOSSARY

Given that this research was conducted using a post-structural lens, I felt that as the researcher it was important to not define but to create an understanding of the meaning of terms I use in this portfolio. Post-structuralist thought believes that truths are created, and that reality must be interpreted (Humes & Bryce, 2003). With this in mind, I want to provide the reader with clarity and a sense of what these key terms mean to me.

Normalcy

Normalcy comes from the word norm and is defined by society's standards of what is considered average by that particular society. Its origins are rooted in 1800's English and are connected to the notion of ideals (Davis, 1997). Given that post-structuralism was developed in the 1960s, as an opposition to structuralism, normalcy is not a word that fits with a post-structural philosophy. Normalcy is a social construct and is defined by the people within a society, thus it is unlikely that what one person sees as normal, is seen by another person in the exact same way. The concept of 'normal' was noted many times in my journal entries, as Jamie longed to be 'normal' and do 'normal things', which was not possible because of his illness. When Jamie would fret about not being normal, I would remind him that no one is normal, and that everyone is dealing with something. I did not know it, but I was comforting Jamie using a post-structuralist lens, by telling him that there are many definitions of normal and that no two 'normals' are alike.

Mental Illness

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Mental illness is hard to define. Even within the medical community, there does not appear to be a clear and concise definition of what mental illness is, and how to define it. In his 1974 book, *The Myth of Mental Illness*, Szasz argues that mental illness does not exist, but is a social construct used to control individuals who display behaviors that deviate from those accepted by society (Granello & Granello, 2000). Although Szasz's book was written over forty years ago, his view of mental illness as a social construct and not an actual illness, may still apply. Coming from a post-structuralist viewpoint, I believe that truth is created, and that there are no absolutes (Humes & Bryce, 2003). If we apply this view to mental illness, we are led to believe that there is no absolute definition of mental illness and that no two individuals experience 'mental illness' in the same way.

Journey

When reviewing the literature to gain an understanding of the term journey, as it relates to patients and caregivers, much of what can be found is connected to the patient experience or patient perspective. Journey is often used to refer to the interactions that occur as the patient moves through the health care system, and can include interactions with people, policies, communications, and the environment (Raffaella, Masella, Viglione & Tartaglini, 2019). Travel times, distance located from a hospital as well as a fragmented approach to how a patient accesses care are also parts of the patient journey (Zucca, Boyes, Newling, Hall & Girgis, 2011). My use of the term journey has a similar connotation, in the sense that it continues and is never-ending. While my time caring for Jamie has ended, my transplant journey continues in a different form, as I use my experience to help others who are going through the transplant journey.

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Family

Like many of the other definitions listed in this glossary, family is also difficult to define. For many years, due to heteronormativity, the term family was narrow, and focused on the white nuclear family –two heterosexual parents and their children. Family is also connected to kinship, dating back multiple years and multiple generations (Settles, Stinemez, Peterson & Sussman, 1999). While these may be the definitions of family that you find in the literature, you will note that throughout my project, there are many different groups whom I refer to as family. The main group is my immediate family – Jamie, my parents, and my sister. I also reference my Toronto family or extended family, which includes aunts, uncles, and cousins. You will note that I discuss ‘family who were not supportive’, in both my short video documentary and my autoethnographic piece. To protect their identity, I will not disclose my connection to them. The other families I reference are groups of people who are not genetically related to me, but who fulfill the role of family by providing love, support, and concern. These families include other patients and caregivers and the transplant team. I highlight many different groups of individuals whom I consider family, thus family is defined by the people within a group and can be defined differently by each person and each group of people.

Caregiver

A caregiver is traditionally defined as anyone who provides unpaid care and support to a friend or family member who is disabled, chronically ill, frail, or elderly (O'Connor, 2007). While this definition provides the basis of what caregiving entails, it omits many of the roles that caregivers may play. When I was caring for Jamie, not only did I provide physical care, but also

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emotional support, encouragement, and companionship. If we break down the word caregiver into its simplest forms – it is someone who gives care. But what is care? Care can come in many forms – a shoulder to cry on, help with personal needs, meal preparation, organization of medications and appointments, and so on. For me, caregiver means providing whatever support is needed by the patient, so for some, it might be physical care; for others, it could be emotional support; and, for others, it could be all of the above. Care is defined by what the patient requires, thus the caregiver role will change from patient to patient, and from one point in time to another, as the patient's needs increase or their condition improves.

Husband

When researching the definition of husband, much of what I found revolved around “a male partner in a marriage” (Webster Dictionary, 2021). This is a simple definition, but when looking at how I use the term husband to describe Jamie, this definition fits. When I call Jamie my husband, I use this term to indicate that we were legally married, and we were in a committed, lifelong partnership. I am cognizant of the fact that not all relationships can be defined in legal or gendered terms, and that there are many different terms for relationships and committed partners.

Patient

It is important to note the word patient that I have used throughout this portfolio. I have used this word to describe those individuals who have relocated and are health care system users who are in need of a heart transplant. I have used this word to describe these individuals as it is

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how they are commonly referred to in the literature as well as in a hospital setting. Despite this I am cognisant with the fact that this does not align with a post structural philosophy and that I view these individuals as people first and patients second.

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CHAPTER 1: INTRODUCTION & SYNTHESIS PAPER

The notion of *home* is vital to a person's sense of self (Borg et al., 2006; Downing, 2008; Marcus 1995). For most individuals, *home* represents a place for growth and development, a place where they have control, and a place where they can balance the need for socialization, while also maintaining privacy. Home plays a critical role in recovery, as it is a secure base where people can heal (Borg et al., 2006). When entering the health care system, many patients and caregivers feel as if they have no control over their lives, which are dictated by doctors, appointments, tests, and medications. Having a place to call home creates a sense of safety, 'normalcy', and routine, and is a place where patients and caregivers have a sense of control. Simple things such as when to get up in the morning, and deciding what to eat, can affect mental health and well-being when others are in control of everything else. Munck, Fridlund & Martensson (2008) state that some caregivers feel as if they have lost their freedom of choice, and as a result their anxiety decreases when they are in their home environment, due to its familiarity and calming atmosphere. A study that interviewed cancer patients had similar findings and listed uncertainty and loss of control over one's life as one of the most common reactions to being diagnosed with an illness (Aoroua, 2003). Gillsjo & Schwartz-Barcott (2011) found that patients feel home is an important place to deliver care due to its comfort, security, and safety. These studies show that *home* plays an important role in the patient and caregiver journey and is the preferred place to be when dealing with a serious illness.

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Little research has been conducted on the effect of *home* in connection to the heart transplant journey. A review of the literature reveals that there are many definitions of home, all of which may be relevant to how patients and caregivers view the concept of *home* in connection to the transplant journey. These definitions include the place where one lives permanently (Mallett, 2004), the family or social unit (Leiter & Durup, 1998), a house, a district or country where someone was born (Case, 1996), and a place where something flourishes (Oxford Dictionary, 2017). Case (1996) provides additional details about *home*, saying that home can include psychological ties to the vicinity around one's dwelling, and is the geographical lens through which one sees and views the world. Home is also defined as a place where one can be at ease, and a place that one is familiar with (Mallett, 2004). Studies focusing on how *home* is connected to the patient journey for those living with 'mental illness' and HIV/AIDS can be found (Borg et al., 2006; Downing, 2005). However, there is a lack of research on the role of *home* – particularly as it relates to heart transplant patients and caregivers. My study aims to fill this gap.

Literature Review

Self, Home, and Environment

Studies focusing on a person's connection to their home environment are used to explore the relationship between *home* and the transplant journey. In 2008, Downing conducted a study where participants who were HIV positive gave him a guided tour of their residences. Downing

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found that four themes regarding the role of *home* emerged: self-expression, control, security, and restoration, all of which echoed the findings of Borg et al.'s study of patients living with mental illness (Downing, 2008). Downing based his work on studies conducted by Cooper Marcus (1995), who examined the self in relation to physical environments. These studies focused on the importance of having a place that belonged to oneself, allowing for self-reflection and privacy and, therefore, decreasing stress. Patients and caregivers who relocate leave their homes and take up temporary residence in hotels or furnished apartments until a transplant occurs. Neither of these living arrangements may provide the patient or caregiver with the sense of a place belonging to them and may cause increased stress levels.

Recognizing that *home* is more than just a physical space is essential when providing support to patients and caregivers who relocate to access transplant care. The home environment represents a person's identity and is linked to security, privacy, and other aspects of a person such as class, ethnicity, and socio-demographic variables (Williams, 2002). Williams quotes Kearns (1993), who says there has never been an adequate analysis of the role of health care, illness, or caregiving in conjunction with the experience of place, nor has there been sufficient work that has adopted a place-centered theoretical perspective. Although Kearns made this statement twenty-five years ago, little has changed as the literature still lacks evidence that research has been conducted in this area.

Williams (2002) notes two different theoretical perspectives - the first, the concept of therapeutic landscapes, and the second, literature related to place identity. Williams describes therapeutic landscapes as the application of cultural geography to explore physical, individual,

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social, and cultural factors that come together in the healing process. Williams describes place identity literature as literature that contextualizes specific discussion of the meaning of home. These concepts will help ensure that interdisciplinary and transdisciplinary approaches are applied in my research. These approaches can be connected to geography, archaeology, cultural studies, and sociology and emphasize the importance of *home* in the healing process.

Home, Environment, and Complex Systems

Undertaking an interdisciplinary approach is the best approach to use when unraveling and exploring complex systems (Newell, 2001). This research involves the health care system, which is difficult to navigate, and requires patients to interact with many different departments, policies, and procedures. This system becomes even more complicated for patients and caregivers who relocate, because in Canada these patients and caregivers are caught between two health care systems – one from the home province and one from the new province. As I discuss further below, these systems do not appear to communicate with each other and often do not have the same coverage or policies. The health insurance from the home province is usually not accepted in the new province, resulting in gaps in care, which causes patients and caregivers to fall through the cracks.

Relocating to access transplant care has implications for patients, caregivers, transplant teams, researchers, and the medical system. Currently, there is limited evidence of the number of patients and caregivers affected by this issue and its effect on the health care system. There is also little literature that examines the connection between transplant and *home*. The purpose of my research is to increase understanding of the connection between *home* and the transplant

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journey for patients and caregivers, while identifying barriers and supports that impact this unique population. Awareness about this issue must be created so that accommodations can be made to support patients and caregivers.

The goal of the research is to create change in three key areas – policy, professional practice, and patient and caregiver well-being. The research can create change in policy at provincial and national levels. Canada is known for its universal health care system, however, within the country, we have thirteen different health plans – all which operate independently and have a variety of policies and coverage. The goal is that this research will suggest that there are issues with multiple health plans and that synonymous coverage across Canada is needed.

When patients and caregivers present at medical facilities, they may have psychosocial needs that must be addressed, in addition to their physical needs. By creating awareness of the challenges patients and caregivers who relocate face, transplant teams may consider and/or commit to increased supports such as social work, resource workers, and patient navigators, who can assist patients and caregivers with finding a place to live, coordination of appointments and adjusting to life in a new city.

In terms of long-term impacts, the goal is that the research will help make the transition from home to a new city easier for patients and caregivers who relocate to access transplant care. The medical field views patient-centered care as the gold standard for care. Taking this one-step forward a more holistic care model called family-centred care must be created. While the patient and the illness should be the primary focus of the transplant team, they are only one piece of the puzzle. The caregiver also plays an important role and must be part of the care plan. Without the

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caregiver, the patient would likely make more trips to the hospital, be in hospital longer, and have more complications. We need to support caregivers, as well as the patient. The findings of this research will lead to more supports being made available to assist patients and caregivers who relocate to access transplant care.

Having personally experienced relocation to access transplant care, I have witnessed the gaps in the system firsthand. Patients and caregivers are often provided little information on the new city, and are expected to find accommodations, make travel arrangements, and sort out finances, in addition to dealing with a serious illness. Transplant teams are often not aware of the stress these individuals are under, and do not realize that additional supports are needed so patients and caregivers can focus on the illness, and not on the other stressors in their lives. As a result, the transplant team are often unaware of their role as a ‘host’, and does not treat the patient and caregiver as their guests. This disconnect often leaves patients and caregivers feeling unsupported, overwhelmed and lost in the health system. A greater understanding and awareness is needed to ensure relocated patients and caregivers are treated as guests by the transplant team who can provided them with knowledge and guidance about their new home. This research is significant because Canada is geographically a large country, and specialized transplant care is only available in a few provinces, thus patients and caregivers will have to relocate to receive the care needed to survive. If more supports were available to address the needs of this population, and transplant teams and other medical professionals, were aware of the unique challenges this population face, then patients and caregivers could focus on what is important – getting better.

An Interdisciplinary Approach

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Spelt et al. (2009) use the term interdisciplinary thinking to refer to the capacity to integrate the knowledge from two or more disciplines, to produce advancement in ways that would have been unlikely through a single discipline. Incorporating knowledge from several disciplines will create more robust research, as the issues being explored cannot be addressed through one field. In terms of relocation, geography will be explored and how Canada's landmass plays a role in where patients and caregivers reside, and how far they must relocate in order to access transplant care. Economics will be considered, as well as the role scarce resources play in our publicly funded health care system. These disciplines will be studied in conjunction with those seen in health-related research – medicine, mental health, psychology, as well as my own lived experience as a caregiver and social worker.

Transdisciplinary research is a process in which members of different fields work together to develop novel, conceptual and methodological frameworks with the potential to produce transcendent theoretical approaches (Klien, 2008). In a transdisciplinary approach, the researcher conducts problem-oriented research involving a more comprehensive range of stakeholders in society (Klien, 2008). Having a wide range of stakeholders is something I value immensely, as the perspective of patients and caregivers is often overlooked in health-related research and medicine. In my work presented in this portfolio, patients and caregivers provide their expert knowledge and skill regarding what it was like to relocate, and how it connects to the concept of *home*. As a social worker, I practice from the belief that the client is the expert, and that our role as professionals is to help guide or facilitate them through their journey. This belief, along with

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the patient and family-centred care model, will demonstrate the importance of this perspective, as it allows for more in-depth insight into the meaning of *home*.

Statement of Problem and Contextualization of the Research

Every year, thousands of Canadians are diagnosed with heart failure, and for many, the only treatment option is a heart transplant. Organ transplants are not available in all provinces in Canada; thus, many patients and caregivers must relocate to access transplant care. These patients and caregivers deal with a severe illness and face the challenge of having to leave home and relocate to an unknown place. The concept of *home* becomes interrupted in the transplant process, thus through a portfolio-style dissertation, I aim to explore: *How is home connected to the transplant journey?*

Theoretical Approach

The approach was conceptualized using a post-structuralist philosophy, which questions the notion of truth, reality, and meaning, and contends that truth is created and there are no absolutes (Humes & Bryce, 2003). This philosophy is congruent with an interpretivist paradigm, which believes that there is no single reality and that reality must be interpreted. This framework aligns with my beliefs that there is no one truth, but many truths. My social work background has provided me with the skills to recognize that each person has their own set of values and beliefs - the reality through which they view the world. I applied these beliefs to the interviews I conducted with patients and caregivers as what one participant saw as the truth was not the same truth as another participant.

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When conducting qualitative research, the data gathered is often subjective, as the information the participants (patients and caregivers) recalled during the interviews was their perception of the events that they experienced. This assumption is congruent with an interpretivist paradigm which believes that truth is subjective. An interpretivist paradigm was used to conduct this research, as individuals in a group create reality; therefore, there are multiple realities. Max Weber (2016) is cited as a significant influence of interpretivism and believed that one could study social actions through interpretive means. Weber based this belief on the understanding that individuals attach subjective meaning and purpose to their actions (Tucker, 2016).

The ideas of Weber influenced my research because they were based on his opposition to positivism. In an interpretivist paradigm, realities are ever changing and are not concrete (Morgan & Smirch, 1980). An interpretivist lens was used to frame the research because it was the most appropriate approach to examine the experiences of patients and caregivers, as what one person sees as the truth is their reality. In contrast, another person who experienced the same phenomena could see it in a completely different way. Each patient and caregiver experience a different reality; thus, the meaning of *home* and its connection to the transplant journey will change depending on the patient or caregiver. The research was influenced by the belief that the outside observer must attempt to relate to a particular group and must understand the meaning that people attach to concepts. In this study, I, the researcher connected my experience with relocation to the relocation experiences of patients and caregivers, while also trying to

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understand the meaning that these individuals give to *home* and relocating to access transplant care.

These principles shaped the research project and guided the interviews and analysis ensuring that I asked open ended questions and allowed the patients and caregivers to tell their truth. I was also cognizant of the role of power differences between myself as the researcher, and the participants, as well as those that patients and caregivers may have experienced within the health care system. The beliefs of post structuralism and interpretivism align with my perspectives as the researcher, as well as the perspectives of the patients and caregivers I interviewed, making both these frameworks an ideal fit for this project.

Methodology and Methods

As the goal of the research was to gain insight into the narratives around patient and caregiver experiences, and the connection between *home* and the heart transplant journey, qualitative methodologies were used. This research was conducted using two methodologies – autoethnography and narrative analysis.

Autoethnography was used as I, the researcher, have personal experience with the studied phenomena (Chapter 3). Autoethnography is a self-narrative that analyzes how the researcher situates themselves within the context of others (Ellis, Adams, & Bochner, 2011). When using an autoethnographic approach, the researcher analyzes their experiences and writes about these experiences, which stems from being part of a culture (Spry, 2001). Autoethnography provides context for why I am conducting this research; it situates me as the researcher, and allows me to

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self-reflect, interpret and understand how my experience relates to the experiences of other patients and caregivers. Autoethnography was only used to analyze my transplant experience, while the rest of the research was analyzed using narrative analysis.

Narrative analysis is a strategy that recognizes the extent to which stories provide insights into our lived experiences (Thorne, 2000). As it is essential to understand the patient and caregiver experiences of relocating to access transplant care, narrative analysis as a method, was chosen to reveal the lived experience of the participants and contribute to the question of *home* that is central to this dissertation (Chapter 4). The narrative analysis allowed patients and caregivers to tell their stories in their own way, and provided me, the researcher, with a clear sense of who the participants were and what their experience was like.

The total number of participants for the study was nineteen (19) – eleven (11) patients and eight (8) caregivers. Participants were from all over Canada, and had relocated within their province, or to another province to access transplant care. Patients and caregivers reported their relocation had lasted from four (4) months to four (4) years and had occurred within the last ten (10) years.

Interviews were conducted with heart transplant patients and caregivers who relocated to access transplant care. The interviews were semi-structured, and asked guided open-ended questions based on an interview guide. The same interview guide was used for both patients and caregivers, which allowed me to compare and contrast responses, explore patient and caregiver perceptions and probe to gather more information, and clarify answers (Barriball & White, 1994). Due to the COVID 19 pandemic, all interviews were conducted over *Zoom Video*

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Conferencing to ensure social distancing. All discussions were audio-recorded and then transcribed verbatim.

To complete the analysis of the interviews, I referred to Taylor & Francis (2013), who suggests using a three-pronged approach when conducting narrative analysis:

- Importance of the stories depicting peoples' lived experience;
- Storytellers and how they narrate their experiences, constructing meaning for themselves and the audience;
- Listeners focusing on the reflective interplay between the narrative practices and environments and sometimes finding deeper meaning by aligning themselves experientially with participant's stories.

Despite outlining a three-pronged approach, Taylor & Francis (2013) note that there is no prescriptive approach to narrative analysis, and what is important is the coding of key themes as they emerge. These themes were the ideas or trends that many participants spoke about during the interviews. For example, many participants spoke about having to find a place to stay in the new city and the stress this caused. Several participants also spoke about how meeting other patients and caregivers helped them during their journey. The repetitive reporting of 'accommodations' and 'other patients and caregivers' resulted in highlighting these items in the transcripts and coding them as themes. I developed a coding strategy using a color-coded highlighter system, as well as tabs to identify themes, allowing for a hands-on, intimate review of the data. It was also important for me to look for similarities and differences among participants'

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responses, especially given that both patients and caregivers were interviewed, allowing me to compare and contrast responses. As the researcher, my role was to make sense of the participant stories, and disseminate these messages to other listeners, as it is by listening to the stories that lived knowledge is shared, insights are gained, and lives are changed (Taylor & Francis, 2013). This was a critical step to ensure that the voices of the patients and caregivers were heard.

Dissertation Organization and Rationale

A dissertation by portfolio was chosen versus a traditional monograph as, I wanted the findings to impact patients and caregivers directly. Given that patients and caregivers are my priority audience, I am displaying my research through a portfolio to ensure that the findings are accessible, concise, and easy to understand. While patients and caregivers are my primary audience, this work focuses on three specific audiences – patients and caregivers, front-line staff, and physicians, researchers and academics. Three elements were chosen for the portfolio – two journal articles and a short video documentary, each highlighting an aspect of the research while targeting a particular audience. While these three elements all have a different focus and are meant to influence different populations, they are all connected, as they focus on the patient and caregiver experience, and their connection to home. Having a variety of methods as the means to disseminate this research will ensure that each audience can review the findings in a variety of ways and in ways that make sense to them. Not only will having a variety of dissemination methods benefit my target audiences, this will also allow my project to reach more people. More information on my dissemination and knowledge transfer plan can be found in Chapter 5. My

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dissertation has been organized into chapters, with each chapter reflecting a piece of the overall portfolio. An overview is provided below.

Chapter 2: Short Video Documentary

A short documentary was created to display the research in an accessible, entertaining, and informative way. A documentary can be defined as the creative treatment of actuality; meaning that we can take an event which has occurred and frame it, using a creative lens (Eitzen, 1995). Documentaries are also described as narratives using photographs and film to explain an event (Plantinga, 2005). It was important for me to use a documentary to highlight the research findings, as a video would be of interest to patients and caregivers, and not just an academic audience. A documentary was also used as it allowed me to tell my story and insert myself into the research, therefore showing why I am studying this topic, and why it is important for viewers to understand the challenges patients and caregivers who relocate face.

The main objective of the documentary was to disseminate knowledge in an impactful way that is easy for anyone to understand. I wanted to ensure that the documentary was visually interesting, thus a videographer was hired to help incorporate video clips, photos, props, and other live-action shots. A script was created outlining my transplant journey, combined with the narrative analysis from patient and caregiver interviews and the autoethnographic piece from my journal writings, which provided an overall picture of the research findings. The documentary will be available on YouTube and through my blog, making it accessible to anyone, particularly patients and caregivers.

Chapter 3: Autoethnography Journal Manuscript

Chapter 3 focuses on my lived experience, using autoethnography to analyze my journal writings and describe what it was like to be a caregiver who relocated with a patient, to access transplant care. This journal manuscript allows the reader to understand my position, not just as a researcher, but also as someone with lived experience in this area and provides insight into why this topic is essential. The target audience for this journal manuscript is researchers, academics, and clinicians who work with heart failure patients.

Using autoethnography, I analyzed journal writings of my transplant journey, which were recorded as the journey unfolded. The journal entries began in 2014 when I relocated with Jamie to access transplant care and ended in 2017 when Jamie received a heart transplant. In total, there were nine hundred and forty-seven (947) journal entries. The analysis of these journals provides the reader with an understanding of the ‘story’ of what it was like to leave home to access transplant care. My journals were handwritten, so similar to the audio recordings of the interviews they were transcribed, analyzed and themes were identified.

To complete the analysis of the autoethnographic piece, techniques set forth by Heewon Chang (2008) were followed. Chang states that the analysis of autoethnography is important because it goes from describing what happened, to explaining how memories can be strung together to explain relationships to others in society. Chang (2008) lists ten strategies that can be used to focus a researcher's efforts on data analysis of autoethnography. They include:

- Search for reoccurring themes and patterns;

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- Look for cultural themes;
- Identify exceptional circumstances;
- Analyze inclusion and omission;
- Connect the present with the past;
- Analyze relationships between self and others;
- Compare yourself with other people's cases;
- Contextualize broadly;
- Compare with social science constructs and ideas;
- Frame with theories.

Chang (2008) notes that researchers do not need to use all ten strategies to complete an autoethnography analysis, and that it is up to the researcher to choose which steps work for them. In my analysis, I focused on identifying common themes and exceptionalities. In doing this, I used Chang's suggestions to analyze the more difficult parts of the transplant journey, such as the relationships with others – particularly certain family members who were not supportive. My relationship with these family members was difficult for me to discuss, however it was important to include, as it was a significant finding in the research. Given the volume of the data, coding was extremely important, as it allowed me to organize my journal entries in a way that had meaning and enabled me to see how my experience with relocation related to others.

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Once the analysis of both the narrative and autoethnography was complete, I then compared my experience to the experience of the patients and caregivers, to determine if my experience was similar to that of other patients and caregivers who had relocated. The connection to others' relocation experiences became evident when I realized that many of the challenges patients and caregivers faced, and the supports they identified were themes found in my journals.

Chapter 4: Narrative Analysis Journal Manuscript

Chapter 4 focuses on the narrative analysis, providing insight into patient and caregiver relocation experiences for heart transplant care, their conceptualization of *home*, and the extent that we use stories to provide insight into the lived experience. The target audience for this journal manuscript is nurses and other front-line staff who work directly with patients and caregivers who relocate.

Using narrative analysis, I conducted qualitative interviews with heart transplant patients and caregivers who relocated to access transplant care. The interviews were semi-structured and asked guided open-ended questions. Due to the COVID 19 pandemic, all interviews were conducted over *Zoom Video Conferencing* to ensure social distancing. All discussions were audio-recorded and then transcribed verbatim. The transcribed interviews were analyzed by hand using note-taking, colour-coding, and organization to identify themes and common phrases, words, or quotes.

Chapter 5: Knowledge Translation and Conclusion

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A knowledge translation plan was created outlining how the research findings will be disseminated to target audiences, which include patients and caregivers, front-line staff and researchers, academics and physicians. It is important to ensure the findings reach patients and caregivers as this is where the findings will have the greatest impact. The short video documentary can be viewed and understood by any audience, and will be available through my blog. A podcast interview geared towards a variety of audiences was recorded and is available to anyone to listen to. Other means of knowledge translation include writing two journal manuscripts that appear in this portfolio – one highlighting the autoethnography and the other focusing on the narrative analysis. Conference presentations also occurred where the research was shared with a variety of audiences including medical staff, researchers, academia, and students.

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CHAPTER 2: SHORT VIDEO DOCUMENTARY

As part of the dissertation by portfolio, students have the option to choose from a variety of elective pieces to display learning and to transfer knowledge. As part of my portfolio, one of the elective pieces I have chosen to share my research findings is a short video documentary. A documentary was chosen to highlight my research findings, as a video would be of interest to patients and caregivers, and not just an academic audience. It was also important that I, as the researcher, insert myself into the research and use my lived experience as a means to create change, show why this topic is of interest, and why this research is important.

The first step in creating the documentary was to decide what information to share. It was important for me to share my story and the findings from the research, while highlighting both aspects of the research project – the autoethnography as well as the narrative analysis. A videographer was hired to help incorporate video clips, photos, props, live-action shots, and music to ensure the documentary was visually appealing and impactful to the audience. A script was written (Appendix D), which includes my transplant journey, the narrative analysis from patient and caregiver interviews and the autoethnography from my journal writings. The documentary provides an overall picture of the research findings and is available on YouTube and my blog, making it is accessible to anyone, particularly patients and caregivers. To watch the video: <https://www.youtube.com/watch?v=EFb0ssp43SE>

CHAPTER 3: AUTOETHNOGRAPHY

Chapter 3 focuses on my lived experience, using autoethnography to analyze my journal writings and describe what it was like to be a caregiver who relocated with a patient to access transplant care. This journal manuscript allows the reader to understand my position, not just as a researcher, but as someone with lived experience in this area, and provides insight into why this topic is essential.

Writing a journal manuscript is one of the requirements for a dissertation by portfolio. This manuscript is prepared for submission to the *Journal of Qualitative Health Research (QHR)*. QHR is a peer-reviewed journal that publishes interdisciplinary research, aims to enhance health care, and further the development and understanding of qualitative research. The readers of this journal are researchers, administrators and others who work in health and social service professions. I have chosen this journal to submit my manuscript to, because of its focus on qualitative research in health care settings. Many of the other health care related journals that I reviewed as possible avenues for publication, were quantitative focused and as a result would not be a good fit for my research. QHR welcomes articles that focus on the illness experience and the caregiver experience, which aligns with my research, while its interdisciplinary focus, aligns as well with the goals of the Royal Roads University, Doctor of Social Sciences Program.

My manuscript meets the guideline requirements for publication within the *Journal of Qualitative Health Research* because my work is original research that has not been published elsewhere. I have completed a title page and abstract, and ensured that my abstract, word count and referencing format meet the requirements set forth by the journal. I have included the

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required funding and conflict of interest acknowledgments, as well as acknowledgement that my study received ethics approval from Royal Roads University Ethics Board. To view this journal:

<https://journals.sagepub.com/home/qhr>. To view the guidelines for submitting to this journal:

<https://journals.sagepub.com/author-instructions/QHR>

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A Caregiver's Perspective of Relocation and the Transplant Journey: An Autoethnography

Abstract

For many heart failure patients, a heart transplant is required. Few hospitals in Canada perform heart transplants; thus, patients and caregivers must relocate to access transplant care. The purpose of this study is to learn from my lived experience as a caregiver and researcher, and to improve the relocation experience. Autoethnography was used to analyze journal writings of my experience relocating with a heart failure patient to access transplant care. From my perspective as a caregiver, I identified challenges and supports associated with relocation, my concepts of home, as well as self-reflection on the transplant journey.

Keywords: Transplant, Caregiver Experience, Relocation, Autoethnography

CHAPTER 4: NARRATIVE ANALYSIS

Chapter 4 focuses on the narrative analysis which was used to reveal the lived experience of the patients and caregivers, who participated in this study, and contribute to the question of *home* that is central to this dissertation. The narrative analysis allowed patients and caregivers to tell their stories in their own way, and provided me, the researcher, with a clear sense of who the participants were and what their experience was like.

Writing a journal manuscript is one of the elective elements for a dissertation by portfolio. This manuscript is prepared for submission to the *Heart and Lung: The Journal of Cardiopulmonary and Acute Care*. *Heart and Lung* is an American peer-reviewed journal that publishes articles focusing on the care of patients who have cardiac or pulmonary illnesses. One of the cardiac issues this journal focuses on is heart failure, including those in and out of the hospital and its readership is primarily nurses who work directly with patients and caregivers, making it a good fit for the narrative analysis manuscript as well as making it an ideal journal in which to publish my research findings. *Heart and Lung* has interdisciplinary and multidisciplinary underpinnings, which also align with the values of the Royal Roads University Doctor of Social Sciences program. I have chosen this journal to submit my manuscript, because of its aim to advance the care of heart failure patients and provide nurses with research that can be applied in a clinical setting.

My manuscript meets the guidelines for *Heart and Lung* because my work is original research that has not been published elsewhere. I have completed a title page and abstract and ensured that the manuscript contained the required sections: methods, results, discussion etc. My

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abstract, word count and referencing format meet the requirements set forth by the journal. I have included the required the funding and conflict of interest acknowledgments as well as the acknowledgement that my study received ethics approval from Royal Roads University Ethics Board. To view this journal: <https://www.journals.elsevier.com/heart-and-lung>. To view the guidelines for this journal: <https://www.elsevier.com/journals/heart-and-lung/0147-9563/guide-for-authors>

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Title: Patient and Caregiver Perspectives on the Connection Between Home and the Transplant Journey: A Narrative Analysis

Declarations of Interest: None

Abstract

Background: For many heart failure patients, a heart transplant is required. Few hospitals in Canada perform heart transplants, thus, patients and caregiver must relocate to access transplant care.

Objective: To learn from patient and caregiver experiences and improve the relocation experience.

Methods: Following a series of 19 interviews with heart failure patients and caregivers, a narrative analysis was used to explore patient and caregiver experiences of relocating to access transplant care.

Results: Patients and caregivers identified three supports during relocation: other patients and caregivers, the transplant team, and family. Rather than linked just to geography, patients and caregivers defined home as friends, family, community, warmth, safety, belonging, and comfort.

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Conclusion: During relocation, patients and caregivers were supported by other patients and caregivers, the transplant team, and family. How these people made them feel: safe, warm, comfortable, and that they belonged is also how patients and caregivers defined home. The supports and definitions of home are connected; thus, a sense of home is inextricably linked to the transplant journey for patients and caregivers.

Keywords: Home, Caregiver, Patient Experience, Narrative Analysis

Highlights:

- Patients and caregivers face challenges when relocating to access transplant care.
- Supports are needed during relocation for both patients and caregivers, so they can focus on medical needs.
- The patient and caregiver perspectives are needed to understand the challenges of relocation.

CHAPTER 5: KNOWLEDGE TRANSLATION & CONCLUSION

Knowledge Translation and Dissemination

Knowledge mobilization (KM) is a broad term that encompasses many activities. However, in basic terms, KM relates to how one integrates research findings into policy and practice, and as a result, links researchers, policymakers, practitioners, and intermediaries, with the goal of improving the use of research in practice (Nutley et al., 2007).

The Social Sciences and Humanities Research Council (SSHRC) defines knowledge mobilization as a reciprocal or complementary flow and uptake of research between researchers, knowledge brokers, and knowledge users outside academia. A KM plan brings the findings from research to the public to create a positive impact. SSHRC also states that KM initiatives inform, advance, and improve the research agenda in terms of academia. Outside academia, KM informs public debate, policy, and practice (Social Sciences and Humanities Research Council, 2019).

In recent years, there has been an interest in strengthening the connection between research, policy, and practice (Levin, 2008). This interest has resulted in researchers being required to include KM plans in their studies, while also summarizing the potential impacts of their work (Cooper, 2015). In a KM plan, several activities are undertaken to disseminate knowledge to a broader audience and to bridge the gap between research and practice (Kislov et al., 2014). The knowledge dissemination plan, which is part of this portfolio, includes three primary elements –a short video documentary and two journal articles. These three elements, in

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turn are directed towards the three target audiences – patients and caregivers, front-line staff, and physicians, researchers, and academics. Additional knowledge dissemination activities as further elements of my KM plan are also outlined below.

Portfolio Elements

Short Video Documentary

The short video documentary highlights my story as a caregiver, who relocated with a patient to access transplant care, and allowed me to insert myself into the research. In this documentary, I discuss the autoethnography and narrative analysis pieces of the research, show how these pieces are connected, and explain how my findings address the research question. To view the short video documentary: <https://www.youtube.com/watch?v=EFb0ssp43SE>

Podcast

I was interviewed by *Living Transplant* podcast, where I shared my transplant journey (Part 1) and talked about my research – both the autoethnography and the narrative analysis (Part 2). *Living Transplant* is a podcast from the *Ajmera Transplant Centre* at *University Health Network (UHN)* that explores transplants through the perspectives of front-line staff, researchers, living donors, recipients, caregivers, and families. The podcast is available to the public, with a target audience of anyone interested in transplantation, living donation, health or medicine. The podcast episodes were released in June 2021. To listen to the podcast, please visit: https://www.uhn.ca/Transplant/Living_Donor_Program/Centre_for_Living_Organ_Donation/What_We_Do/Pages/Living_Transplant_Podcast.aspx

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Blog

Initially, I envisioned creating a website to disseminate the research findings. However, I decided not to go this route, as my portfolio was more suited to allow for a back-and-forth flow of information versus the stagnate nature of a website. A blog was created to summarize the research findings and to provide downloadable content such as the short video documentary, the *Living Transplant* podcast, and content from my journal articles. A blog was chosen over a traditional website due to a blog being typically more interactive, while encouraging networking and sharing of information. Websites are unilateral and do not offer the same opportunity for people to engage with each other. The content generated through the blog will allow knowledge to flow more effectively (McGowan et al., 2012). The blog will provide an opportunity for real-time dialogue and allow people to communicate, share ideas, and engage with each other.

Phipps, Jensen, & Myers (2012) believe that digital technologies have created new opportunities for scholars to disseminate research beyond traditional audiences. Given that one of my target audiences is patients and caregivers, a blog is a logical choice for my dissemination plan. The public is familiar with blogs; therefore, it is an effective way to reach this audience. Other benefits of using a blog to disseminate my research findings include the ability to reach a large audience, cost-effectiveness, ability to manage the blog from anywhere, and little upkeep and maintenance is required. The use of digital technology is also beneficial, as it will allow me to disseminate my findings as they become available instead of waiting to complete a final product. To access the blog please visit: www.homeandhearts.ca

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Conferences

To ensure that my findings reached academics, researchers, and medical professionals, abstracts were submitted to conferences that focus on topics such as qualitative research, transplant, cardiology, and social work. To date I have presented/been accepted to the following conferences:

- The *International Congress of Qualitative Inquiry (ICQI)* – May 2021
- The *Canadian Bioethics Society Conference (CBS)* - May 2021
- The *Canadian Association of Social Work Education (CASWE)* - June 2021
- The *International Conference on Interdisciplinary Social Sciences* - July 2021.

During the *ICQI* conference and the *International Conference on Interdisciplinary Social Sciences*, I presented primarily on the autoethnography piece of my research, focusing on my story, the analysis of my journals, and what it was like to be a caregiver who relocated with a patient to access transplant care. The audiences of these conferences were qualitative scholars and researchers from a variety of backgrounds. At the *CSWE* conference and the *CBS* conference, my presentation focused on the narrative analysis piece of the research, specifically on the findings from the patient and caregiver interviews. I also provided some information on my personal connection to the research, to give context, and to inform the audience that I have lived experience in this topic. The audiences of these conferences were primarily social workers, bioethicists, clinicians, students, and researchers.

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Journal Manuscripts

While conferences were one way to reach my target audience of academics, researchers, and medical professionals, the two manuscripts that I have included as part of this portfolio are also geared towards a more academic audience. These journal manuscripts will be submitted to *The Journal of Qualitative Research*, whose audience includes medical professionals, administrators and others who work in the health sector, as well as *Heart and Lung: The Journal of Cardiopulmonary and Acute Care*, whose audience is primarily nurses.

Audience – Patients and Caregivers (Current and Future)

I targeted much of my messaging towards a patient and caregiver population because these are the people who will benefit most from the research. The short video documentary, the podcast, and the blog are geared towards this population and are facilitated in a way that speaks to the patient and caregiver and not to a medical audience. My blog is not only a means to share research findings, but allows patients and caregivers to connect with each other, and will be used to share my short video documentary, the podcast, and other research-related content. While my knowledge translation focus is geared towards patients and caregivers who are experiencing relocation, my research will also benefit those who are early in their transplant journey. When first diagnosed with heart failure patients and caregivers often feel overwhelmed, shocked, lost, and confused. My research will provide information to heart failure patients and caregivers, so they are aware of what may be required in the future, and provide them with the sense that they are not alone and that others have gone through diagnosis, treatment, and relocation. Having my

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research easily accessible will allow patients and caregivers to share this information with family and friends, as well as others who may not be familiar with heart failure or transplant. This sharing of information will be beneficial to patients and caregivers, as it will allow them to create awareness and help their families and loved ones understand the transplant journey and be in a better position to provide support.

Audience – Front Line Staff

Front line staff are the first point of contact for patients and caregivers when they begin their transplant journey. Therefore, knowing the findings of my study will allow staff to assist patients and caregivers in ways that may not have been thought of before. Knowing the findings of my research may change the way staff view patients and caregivers who relocate. When a patient or caregiver presents at a hospital and is angry, upset, or disengaged, staff often rush to label the patient or caregiver as ‘non-compliant’ without stopping to ask why the patient or caregiver is acting this way. As my research suggests, these behaviours are usually not related to the medical issue, but are related to other stressors the patient or caregiver is facing, such as finding a place to live, worrying about limited finances, or having little support in a new city.

A greater understanding of the connection between home and the patient and caregiver journey is needed to ensure that supports are available. Having this knowledge will allow staff to be more aware of the unique needs of this population, which could result in greater understanding and empathy. Front line staff are the target audience for one of the journal articles, which focuses on the narrative analysis, specifically, the patient and caregivers’ interviews that discuss what it was like to relocate as, and with a patient to access transplant care. This journal

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article has been submitted to *Heart and Lung: The Journal of Cardiopulmonary and Acute Care*, whose audience is primarily nurses.

Audience – Physicians, Researchers, Academics and Students

Physicians, researchers, academics, and students are another group who I have shared my research with, primarily through the journal articles and conference presentations. My research is significant because it contributes new knowledge to the field, as there does not appear to be any literature focusing on heart failure/transplant/relocation that uses autoethnography to capture, particularly the caregiver's experience. This research is also unique because it was conducted by me, a researcher with lived experience as a caregiver, under the supervision of a heart transplant patient and a committee member who was a caregiver of a heart patient. No other studies exist where the research is undertaken and supervised by individuals with such in-depth lived experience, making my research truly unique and filling a gap that currently exists in the literature.

Discussion

My research project stemmed from my personal experience as a caregiver who relocated with my husband Jamie to access a heart transplant. As a result of this experience, I knew that patients and caregivers who relocate experience the transplant journey differently than those who receive care closer to home. When discharged from the hospital, patients and caregivers like us return to a hotel room or rented apartment without our families and loved ones, while those who receive care closer to home, get to return to their houses, families, and lives. When I started my

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transplant journey, *home* meant a geographical place – a province like Newfoundland, or a physical structure or place that people went to. As I dug deeper into the research and started putting the pieces together, I began to realize that *home* is not tied to a physical place. It is not concrete, but more abstract and more about feelings and emotions than a physical thing. *Home* is about people and when I look back, it is the people that connect everything – Newfoundland is known for its people, my transplant journey was made easier by my family, other patients, and caregivers, and the transplant team.

The research question I sought to answer was: how is *home* connected to the transplant journey? The three elements I have chosen for this portfolio the short video documentary and the two journal articles along with the introduction and conclusion, show that *home* is connected to the transplant journey. The narrative analysis focuses on the patient and caregiver stories, their challenges and supports during relocation, and how they define home and highlights that home is connected to people and feelings. The autoethnography shares my transplant journey and analyzes my journals, which describe what Jamie and I experienced when we relocated. This manuscript illustrates how early in my transplant journey, *home* for me, was a physical construct, but as the journey unfolded my perception of *home* changed, as I realized that *home* can be made wherever you are, as long as you are surrounded by people who love and support you. Finally, the short video documentary ties everything together and explains how my personal experience influenced the research and how both pieces are connected.

It was very important to me that the research findings reach the people it will help the most – patients and caregivers. It is for this reason that I have chosen to complete a dissertation

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by portfolio and include elements that will appeal to a general audience. As you can see from my knowledge translation plan, I have disseminated the research using a blog and a podcast, which are part of mainstream culture and user-friendly. I also wanted to ensure my research appealed to medical, research, and academic audiences, so in addition to the other dissemination elements, I have written two journal articles which I have included in this portfolio and presented my research findings at two national and two international conferences.

The goal of my research was to create awareness of the unique challenges that patients and caregivers who relocate face and to increase supports to ensure that the needs of this population are met. The conference presentations and journal articles will help make transplant teams among others, aware of these issues and that supports such as mental health support, logistical support, and peer-to-peer support are needed. The blog and podcast will help ensure that patients and caregivers know that they are not alone and will provide an opportunity for this population to connect with each other and share their experiences.

Conclusion

This research project was always so much more to me than just a thesis. It was a legacy project and a tribute to Jamie. As I sit here writing this final piece, I think of Jamie and how much he wanted me to go back to school to fix a broken system. I am confident that while I have yet to fix the system, I have made a difference. This project has provided a platform, not just for my voice, but also for the voices of other patients and caregivers who shared their stories and experiences with me as part of this project. Their willingness to talk about the challenges they faced during their relocation, as well as the supports that helped them along the way, and their

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definitions of home, gave me the courage to open up my journals and write about my personal experiences. This project has allowed me to see that *home* can be anywhere, and that *home* is something we create. Not only did this learning help me process and comprehend what happened, it has also allowed me to realize that while Toronto is now my home, Newfoundland can be my home as well. I began this project by calling it “Home is Where the Heart Is” and I am ending it with confidence that this statement is true.

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EPILOGUE

I can't believe it. Tomorrow I go back to Toronto General. Not as a patient. Not as a caregiver but as staff. Not only am I going back to Toronto General but I'm going back to transplant where it all started!
February 18, 2019

As I have stated throughout the pieces of my portfolio, the purpose of completing a Ph.D. was to use my experience to create change and help others. While completing a doctorate is one way to do this, going back to where Jamie and my transplant journey began is another.

Toronto General Hospital is part of the University Health Network and is located in downtown Toronto. It is one of the leading hospitals in cardiac care, organ transplants, and cares for patients with complex needs (Toronto General Hospital, 2021). Its cardiac and transplant programs are among the top in the world, and the hospital was ranked number four in the world by Newsweek in 2020 (UHN Foundation, 2021).

Despite all its accolades, Jamie and I always felt that Toronto General was home. From our early days as a new patient and caregiver, hearing the word 'transplant' for the first time, to becoming seasoned veterans of the heart failure program, we always felt a sense of safety, comfort, and security inside the hospital. The staff were always friendly and happy to see us, and Toronto General was a place where we would spend time with our friends (the other patients and caregivers). Koleszar Green (2018) notes that the role of a host is to hold guests up so they do not fall down, and to teach them to hunt, farm, survive, and live in this place until they are strong

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enough to support themselves. For Jamie and I, the hospital, the transplant team, and other patients and caregivers were our hosts when we first arrived in Toronto. They supported us mentally and emotionally, showed us what to expect as a patient and caregiver, and were our rock, until we learned how to navigate the transplant journey on our own.

One of the reasons why I accepted a position in the transplant program at Toronto General Hospital, was that I wanted to ensure other patients and caregivers felt a sense of home when they came to the hospital, which can be a scary and intimidating place. I wanted other patients and caregivers to feel like Jamie and I did when we first walked through the doors – that we were supported, well cared for, and loved. While this is one of the reasons why I wanted to work in the transplant program, the other reason I wanted to be there was more personal – I wanted to be surrounded by, and work with other ‘Jamie’s’ and ‘Heather’s’. Working in this program is, and always will be, so much more than just a job. It is humbling, and I feel privileged to play a small part in the lives of other patients and caregivers who are on their own transplant journeys.

When I started working at the hospital, I was in year two of my doctoral program. I had attended two residencies on campus, finished my coursework, and was working on my comprehensive exams. The first year of the doctoral program was incredibly difficult. As mentioned, I started the program two months after Jamie passed. Residency was hard. I had just lost my husband, moved from our temporary home in Toronto to our original home in Newfoundland, and then flew across the country for school. I felt very alone. During the first few weeks of residency, I did not tell anyone about Jamie or my story. I felt it was easier this way.

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Residency was a blur. I do not remember much, other than feeling out of place and that I did not belong there. As I sat in class each day, listening to classmates talk about theory and methodology, I wondered if there had been a mistake, and that I had been accepted into the program by accident. What I was experiencing was imposter syndrome — feeling that I did not belong in that classroom, that I was not smart enough, and that soon, people would realize I should not have been in the program (Breeze, 2018). While the description of these feelings is how I felt, what I was most afraid of was not people finding out that I was not competent enough to be in the program. My biggest fear was that people would discover my personal connection to my research topic, and at the time, the only reason I was attending was that I had told Jamie I would, and the guilt of not fulfilling this promise was the factor motivating me to get up and go to class each and every day.

As time went on school started to become more bearable and became my inspiration to keep going. It gave me something to focus on and something to work towards. In simplest terms, Jamie had been my ‘project’ – something I focused all my energy into, something that gave me purpose, and something I was passionate about. When Jamie passed, I did not know how to fill my time. I can remember getting up each day and questioning what it was I was supposed to do now that I did not have to measure sodium and fluids, change dressings, and count medications. I was lost but going back to school gave me direction. School was my new ‘project’ that kept me busy, gave me purpose, and given that it focused on our transplant journey it was something I was deeply passionate about.

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The concept of grief has existed for over one hundred years; Freud first described this phenomenon in 1915, when he defined grief as a bereaved person's gradual withdrawal of energy due to the loss of an object or person (Jacob, 1993). While Freud's definition was basic and developed many years ago, grief is still a concept that is often misunderstood, yet is a universal feeling that we all experience at one point or another. When looking at the literature, many different definitions of grief can be found. Grief can be described as an adaptation response to illness, an acute or series of crises, and as a syndrome (Cowles and Rodgers, 1991). Maciejewski et al. (2007) describe grief simply as a psychological response to a loss. No matter how you define grief, grief for me was an unpredictable, hard and lonely experience. I felt empty and I questioned every decision I had made and overthought every move I was about to make. Experiencing grief as a young widow is even harder. When Jamie passed away, I was 34. Most of my friends were newly married and had just started having families. There were few people who 'got' what it was like to lose your husband, and those that did were more than twice my age and had spent many years with the person they loved.

When completing my social work degree, we had learned about grief and had studied the stages of grief, which were developed by Kubler-Ross and include: denial, anger, bargaining, depression, and acceptance (Kubler-Ross and Kessler, 2005). As a 'mental health expert', I thought I had a good understanding of how to deal with grief. I was wrong. In my early grief, I attended counseling sessions with a therapist. While she was a wonderful listener and provided great suggestions on how to cope with my loss, we did not get past Kubler-Ross's anger stage. I was mad. I was mad at Jamie for dying. I was mad at the unsupportive family for causing so

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much stress and I was mad that I did not get to live ‘happily ever after’ and grow old with the person I loved.

What I did not realize at the time was that analyzing and processing what happened to me would prove to be therapeutic and healing. This process made me realize some of the things I had ‘missed’ while caring for Jamie. The most significant one was that I had no idea how stressed I was during our three years in Toronto. Most of the time I came across as put together and coping well, but in reality, I was not. It was not until I analyzed my journals that I realized how many times I noted that I was stressed, anxious, and physically ill – headaches, stomach problems, pains in the chest. I also did not realize how exhausted I was. While I did not note this in my findings, I was napping almost every day, which is not something I did prior to caring for Jamie.

As someone who does not usually express their feelings verbally or outward, I turned to my journals as a means to express myself. When analyzing the journals, I was surprised about how much I wrote about my feelings – scared, frustrated, or worried. I especially found journal writing to be helpful when dealing with topics that I was not comfortable speaking about out loud – the certain family members who were unsupportive, as well as my feelings of having to give up my life and feeling at times jealous of Jamie.

Doing an autoethnography was not easy, and there were many times that I asked ‘why am I doing this?’ Ellis (1999) states that the self-questioning associated with autoethnography is extremely difficult, and so is confronting things that the writer may not be proud of. Ellis goes on to say that honest autoethnographic exploration generates fears, self-doubts, and emotional pain.

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Completing this autoethnography was challenging, but finding that others like Ellis also confronted these same fears provided me with a sense of comfort and pushed me to continue writing this piece of the project.

The autoethnography was just one piece of the portfolio that helped me deal with my loss. Interviewing the other patients and caregivers and hearing their stories was extremely comforting. The word story is derived from Greek origins meaning knowledge, knowing and wisdom (Yoder-Wise and Kowalski, 2003). I am a firm believer that stories have the power to transfer knowledge and learning, and the ability to create change. Stories also have the power to elicit emotional responses, communicate a common history and build and create support (Kent, 2015).

Hearing the stories of other patients and caregivers who had gone through relocation, made me realize that I was not alone. While everyone's story is unique, many of the things that the participants experienced, were things Jamie and I had also gone through during our transplant journey. When you lose someone you love, you question yourself, and this was a common theme throughout my transplant journey – was I making the right decision? Was this what was best for Jamie? When he died these questions became more profound – Did I do the right thing? Did I do everything in my power to keep Jamie alive? Hearing the challenges that the other patients and caregivers faced, and learning of their experiences, made me realize that I did the best I could, and that I did what most others would do when in the same situation. What was also moving for me, was that when listening to the stories, I could identify a piece of Jamie and I in each and every one of them, whether it was a patient who used a quote that Jamie always said, or a

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caregiver who described their struggles in the same way I did. I felt that our story was in each and every interview, which provided me with a sense of comfort and calm, and let me know that I was doing the right thing.

As this chapter of the transplant journey comes to an end, I am reminded that this too is just a chapter, and that more of my transplant journey is yet to come. I am beyond grateful for all the support I have received along the way. The people in my life – my family, other patients and caregivers and the transplant team, who continue to make me feel at home, regardless of where I am. Most importantly, I thank Jamie for choosing me to experience the transplant journey with him, because without Jamie this story would have never begun.

...if I can do it, anybody can do it...you wouldn't wish for it [heart condition], but I don't think it's a complete... death sentence either. It's gonna give you a lot of trouble, and you're gonna have a lot of hard times, your gonna have lots of ups and downs, but ...you manage to find your way, you manage to deal with it.... I believe I got it [heart disease] cause I can handle it...I just deal with it...Friends say 'I don't know if I'd be ale to do what you're doing. But really, if you want to live, you'll do whatever you have too. If you don't want to live, if you think going through all of this is too much of a hassle, and you just think it's easier just to kind of give up and lie down and die, well that's your choice. But for me it doesn't make any sense. I got too much stuff to do yet. Jamie Wilkinson, 2015

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APPENDIX A: PARTICIPANT RECRUITMENT POSTER

**HEART TRANSPLANT
RECIPIENTS & CAREGIVERS**

STUDY ON **HOME & RELOCATING**
TO ACCESS TRANSPLANT CARE



Are you a **heart** transplant recipient or a caregiver of a recipient who had to **relocate to access transplant care?**

Then we want to hear from you!

You are invited to participate in an interview (1-2 hours) to tell your story. We are interested to learn what home means to you and how it is connected to the transplant journey.

The purpose of the study is to gain a better understanding of how the concept of home is connected to the transplant journey, and what is needed to support patients and caregivers who relocate to access transplant care.

If you are interested in participating contact:

HEATHER LANNON

709-690-9511 | heatherlannon@hotmail.com

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APPENDIX B: PARTICIPANT CONSENT FORM

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Home Is Where the Heart Is: The Connection Between Home and the Transplant Journey

Researcher: Heather Lannon, M.S.W, R.S.W, DocSocSci (C), Royal Roads University

Phone: XXXXXXXXXX

Email: XXXXXXXXX

Supervisor: Dr. Jillianne Code – Assistant Professor, University of British Columbia

Phone: XXXXXXXXX

Email: XXXXXXXX

Introduction:

You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on the study's risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the researcher to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends and family. Participation in this study is voluntary.

Background/Purpose:

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Every year thousands of Canadians are diagnosed with heart failure and for many, the only treatment option is a heart transplant. Organ transplants are not available in all provinces in Canada; therefore, many patients and caregivers must relocate to access transplant care. These patients and caregivers not only deal with the stress of a serious illness, but also face the challenge of having to leave home and relocate to an unknown place.

You have been asked to participate in this study because you have indicated that you would be interested in participating in an interview.

Information gained from this study will help to better address the needs of patients and caregivers who relocate to access transplant care. It will also help the medical team to be better at answering questions and concerns and to deal with the health-related needs of patients similar to yourself. I will be sharing the findings of this study with other patients, caregivers and medical staff in order to better serve patients and families.

This research will form the researchers Doctoral Dissertation for the Doctoral of Social Science Program at Royal Roads University and will be publicly available.

Procedures:

You will be asked to participate in **an interview** to discuss what it was like for you to relocate to access transplant care. I am interested in hearing your story and learning about your experience. During the interview I will ask you several questions to keep us on track, however you are welcome to tell your story in whatever manner makes you most comfortable. I will audiotape the interview and may take handwritten notes.

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Each interview will be audio recorded. Only the researcher will have access to the audiotapes. Once the tapes have been transcribed, the tapes will be destroyed.

Risks:

There are no risks to taking part in this study. Should you feel uncomfortable or distressed during the interview, you can voice your concern immediately to the researcher. Additionally, community supports have been identified for you to connect with if needed.

Benefits:

You may not receive any direct benefits from taking part in this study. Information learned from this study may help to better understand how home is connected to the transplant journey. With this information, improvements may be made to the types of support that patients and caregivers can avail of when relocating to access transplant care.

Alternatives to Being in the Study:

You simply may decide not to be involved in this study. The researcher will talk with you about this option if you wish.

Confidentiality:

Personal Health Information

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If you agree to participate in this study, the researcher will look at your personal health information and collect only the information needed for the study. Personal health information is any information that could be used to identify you and includes your:

- name,
- telephone number (so I can contact you)
- Other demographic information

The information that is collected for the study will be kept in a locked and secure area by the researcher for 10 years. Only the researcher will be allowed to look at your records.

Study Information that Does Not Identify You

Data from this study will be entered into a computerized database. Only the researcher with a password will be allowed to enter data. All study data are identified by code, not by your name. A list linking your study number with your name will be kept by the researcher in a secure place, separate from your study file. Efforts will be made to keep your personal information private. However, I cannot guarantee complete confidentiality. You will be identified by a code, and personal information from your records will not be released without your written permission. All information will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be identified in any publications or presentations that may come from this study.

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Transcribed audiotapes will be kept with the researcher (in a secure a locked cabinet) for the duration of the study. Once the transcriptions have been analyzed and verified, the audiotapes will be destroyed.

Voluntary Participation:

Your participation in this study is voluntary. You may withdraw from the study at any time. If you decide to withdraw, your care will not be affected in any way. I will provide you with any new information that is learned during the study that may affect your decision to stay in the study. If you decide to withdraw from the study, the information about you that was collected before you leave the study will still be used in order to answer the research question. No new information will be collected unless this is required to fulfill safety reporting obligations.

Rights as a Participant:

By signing this form you do not give up any of your legal rights against the researcher for compensation, nor does this form relieve the researcher of their legal and professional responsibilities.

Conflict of Interest:

The researcher has an interest in completing this study. Their interests should not influence your decision to participate in this study. You should not feel pressured to join this study.

Questions About the Study:

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If you have any questions, concerns or would like to speak to the researcher for any reason, please call: Heather Lannon at 709 690 9511

If you have any questions about your rights as a research participant or have concerns about this study, call the Royal Roads University Research Ethics Board (RRU REB) at 250-391-2600 ext. 4425. The REB is a group of people who oversee the ethical conduct of research studies. The RRU REB is not part of the study. Everything that you discuss will be kept confidential.

You will be given a signed copy of this consent form.

Consent:

This study has been explained to me and any questions I had have been answered.

I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

Print Study Participant's Name

Signature

Date

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

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Print Name of Person Obtaining Consent Signature Date

Was the participant assisted during the consent process? YES NO

If **YES**, please check the relevant box and complete the signature space below:

The person signing below acted as an interpreter for the participant during the consent process and attests that the study as set out in this form was accurately interpreted and has had any questions answered.

Print Name of Interpreter

Signature

Date

Relationship to Participant

Language

APPENDIX C: INTERVIEW GUIDE

INTERVIEW GUIDE

Thank you for agreeing to participate in this interview. There are several reasons behind the study that I am conducting. One of them is to explore patient and caregivers' experiences about having to relocate to access transplant care. Learning more about those experiences and how home is connected to the transplant journey will create a better understanding of the needs of these patients and caregivers.

I will ask you a number of questions, which you will answer to the best of your ability. There are no right or wrong answers. I will be recording this interview, but no one other than me will have access to the tapes or know how you answered these questions. This recording will be transcribed, word-for-word by a professional transcriptionist. Transcription is taking the words and dialogue on the audio tape and typing it word for word. I will use the word-for-word transcript of the discussion for analysis. All names and identifiers will be deleted during the transcription process. If you become uncomfortable and want to stop the interview, let me know and we will stop immediately. So, let's get started.

Do you have any questions or comments before we begin?

1. Can you tell me about your transplant journey?
2. What does home mean to you?
3. How did leaving home to access transplant care affect you? (Positive and Negative)
4. When you relocated were there things that helped?

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- a. If yes, what helped?
 - b. If no, what would have been helpful?
5. When you relocated were there things that were challenging?
 - a. If yes, what were they?
6. If you could do it all over again would you do anything different?
7. Is there anything else you think I should know or understand better?
8. Is there anything you would like to ask me?

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APPENDIX D: SHORT VIDEO DOCUMENTARY SCRIPT

Video Script

My Story

Intro

My transplant journey began long before I heard the word transplant, or even knew what transplant meant.

It began before I became intimately involved with the health system and before I really understood the true meaning of life and death.

My transplant journey began about 20 years ago when I first met Jamie.

At the time, I had no idea that Jamie would not only introduce me to transplant, but would alter the course of my life, and lead me on an amazing journey.

Early Life

I was born and raised in St. John's NL.

Growing up my life was pretty average and my family consisted of my mom, dad, sister, and I.

After high school, I attended university to study social work, and it was during this time that I met Jamie.

Jamie Early Life

Jamie grew up in a small town just outside of St. John's called Flatrock.

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Jamie was born with a congenital heart defect and was not expected to survive. He underwent surgery when he was a year old and it was believed that he would go on to live a normal life.

Dating

Jamie and I met while working at a summer day camp and begin dating several years later.

About a year into our relationship Jamie's health began to deteriorate. He started experiencing shortness of breath and his heart would race.

As someone with no prior experience with illness, these episodes scared me and caused me to worry.

Engagement

By 2010, we were engaged and Jamie's health continued to deteriorate and his trips to the ER became more frequent.

I felt as if I was always on call. Waiting to take Jamie to the hospital and always having to cancel plans.

Wedding

In 2012, we were due to get married and as the wedding neared Jamie got sicker and sicker. He couldn't eat, sleep, or walk. We didn't know it at the time, but Jamie was dying.

A trip to the ER revealed the worst. Jamie was in heart failure and there was nothing doctors in NL could do to help him. He needed to go to Toronto for specialized care.

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I didn't know it at the time – but my transplant journey was about to begin.

Having to leave NL and board a plane, all while hoping your loved one was still alive, was one of the most stressful things I have ever done. I was overwhelmed and in a matter of minutes had to figure out flights, accommodations, and time off work.

The heart team in Toronto was able to stabilize Jamie and we flew home and got married on July 27, 2012.

Maintenance

From 2012 – 2014 Jamie and I made 10 trips to Toronto so he could get the care he needed.

While going back and forth to Toronto was financially draining, it allowed us to remain in NL, spend time with family and enjoy doing things we loved.

Relocation

In 2014, Jamie's health again deteriorated and the medical team determined it was best to relocate to Toronto.

This move was hard. Jamie hated Toronto, wanted to go home, and became depressed.

Much of my time was spent trying to calm and reassure Jamie, all while dealing with my own homesickness.

During this time the medical challenges continued with Jamie having his thyroid removed, a code blue distress call and a pacemaker and defibrillator implanted.

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The risk of death was always present and I constantly felt the pressure of having Jamie's life in my hands while also yearning to have my life own life back.

Lennon- the VAD

After several months in Toronto, Jamie's condition did not improve. A VAD (Ventricle Assist Device) a heart pump was implanted to help Jamie.

The procedure was risky. There was only a 50% chance of survival.

I agonized over this decision, second-guessing myself and continuously wondering did we make the right choice?

Jamie survived, and several months later I begin to see signs of the old Jamie, which was a huge relief for me as I could now finally do things for myself and not have to constantly put myself on the backburner.

Jamie continued to do well with the VAD and we settled into life in Toronto.

Transplant

On May 18, 2017 - we got the call that a new heart had been found.

I was flooded with emotions – panic, excitement, relief and hope.

Two days later Jamie was taken to surgery.

I felt a sense of joy as this chapter of our journey was about to close, and we would soon start a new chapter as we moved forward with our lives.

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Unfortunately, the surgery was not a success.

Hearing this made everything stop. I was in shock. This could not be happening.

After surgery Jamie was brought to ICU and placed on life support. After several days of no improvement, I made the decision to turn off the machines.

Jamie died on May 23, 2017. He was 39 years old.

Segway

When Jamie died, I assumed (and probably hoped) that my transplant journey was over.

I was wrong. My experience with Jamie was just a chapter of my transplant journey, which continues to this day.

Staying connected to transplant has allowed me to stay connected to Jamie, to use my experience to help others and to heal myself from this tragic loss.

So, 2 months after Jamie's death I begin another chapter in my transplant journey.

I begin the Doctor of Social Sciences program at Royal Roads University – studying how home is connected to the transplant journey.

Research

So why is my research important?

One of the reasons one undertakes doctoral studies is to add new knowledge to the field.

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When I conducted my literature review, I realized there was little research available that focused on the connection between transplant and home.

My research is also important because it is being conducted by someone with lived experience (caregiver), while under the supervision of someone with lived experience (heart transplant recipient).

Again, there does not appear to be any research currently that was conducted by individuals with such lived experience.

This makes my research truly unique.

What do we know?

We know that (according to Heart and Stroke Foundation 2016) on average 50,000 people in Canada are diagnosed with heart failure each year.

And for many, heart failure will lead to a heart transplant.

We also know that there are only eight transplant centers in the country that perform heart transplants – eight in all of Canada.

So, it is enviable that patients and caregivers will need to relocate to access transplant care.

Methodology

To conduct my research, I used two methodologies – narrative analysis and autoethnography.

Narrative Analysis

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I chose narrative analysis because it was important to me to have patients and caregivers share their stories.

Stories give insight into the lived experience, and I wanted patients and caregivers to be able to tell their stories in a way that made sense to them.

Autoethnography

I chose autoethnography because it was important to me to use my experience to create change.

In autoethnography the researcher explores their experience and connects it to the wider culture – which in my case, allowed me to connect my story to the stories of other patients and caregivers.

Ethics

I received ethics approval from Royal Roads University and then begin my research by recruiting participants for my study.

Recruitment

One benefit of being part of the transplant community was that I had many networks already available to recruit participants for my study.

I used several methods to promote my study including: social media, Facebook groups, emails to transplant agencies as well as word of mouth.

What I did

Interviews

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I conducted 19 interviews over Zoom (due to COVID).

11 of the participants were patients and 8 were caregivers.

Participants were from all over Canada; however, the majority were from NL – which makes sense given my connection and the lack of transplant centers in the eastern region.

I audio recorded the interviews, transcribed, them and identified the themes.

Autoethnography

I used autoethnography to analyze journal writings that I recorded as my transplant journey took place.

The journal entries begin in 2014 when I relocated to Toronto and ended in 2017 when Jamie was transplanted.

In total there were 947 journal entries.

These journals were hard written, so like the interviews, I transcribed them and identified themes.

What did I find?

From the interviews as well as my journals I found 3 main things:

1. Challenges that patients, caregivers and I faced when relocating to access transplant care
2. Supports and things that helped patients, caregivers, and myself during the relocation
3. How patients, caregivers and I defined home

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From the interviews:

Challenges

Patients and caregivers identified four areas that they found most challenging:

1. Accommodations – the stress of finding a place as well as the cost of renting in a large city
2. Finances – the cost of medications, rent in the new city, while also having to pay bills at home
3. Lack of mental health supports for patients, caregivers, and families
4. Being an out of province patient – lack of coordination/collaboration between provinces, coverage, and benefits

Supports

Despite the challenges, there were three things that the patients and caregivers found helped them:

1. Connecting with other patients and caregivers – “people like me” who got what it’s like to go through relocation and transplant
2. Family – especially the caregivers who relocated with the patients, as well as family
3. Transplant team – who treated patients and caregivers like people (not like patients) and provided care not just to the patient but to the caregiver as well.

Home

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Patients and caregivers defined home using words such as family, friends, community, warmth, comfort, safety, and belonging.

From my journals:

Challenges

Most of the things I found challenging during my relocation were similar to those reported by patients and caregivers:

1. Out of Province Patient – funding, coverage and benefits do not only lack coordination – but are also cumbersome, disjointed and time-consuming. Much of my time was spent completing paperwork and dealing with issues related to drug coverage and disability payments.
2. Finances and accommodation were also in terms of finding a place to live as well as costs associated with living in Toronto, while also maintaining things in NL

One of the challenges that I experienced that was not noted by the patients and caregivers was:

1. Lack of support from specific family members – there were some family members who were unsupportive and just didn't get the transplant journey which created a significant amount of stress for Jamie and I.

Supports

The things that I found most helpful during relocation were also what patients and caregivers found helped the most:

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1. Family – both immediate and extended who would visit us in Toronto, and helped keep things afloat back in NL. And those on the ground who made sure all our needs were met
2. Transplant team – became our family and provided not just medical care but emotional support and showed kindness, compassion and concern.
3. Other patients and caregivers – meeting other patients and caregivers who welcomed us into the transplant community and provided a sense of hope.

Home

While I did not include a definition of home in my journal writings, it was obvious that when I spoke about home - home was NL, my parent's house as well as my house in NL.

What does all this mean?

I want you to think about how patients and caregivers defined home:

1. Feelings: warmth, safety, comfort, and belonging
2. People – friends, family, and community

And also think back to my initial thoughts about home being a province and physical place.

I also want you to think about the supports and things patients, caregivers and I found most helpful during the relocation:

1. Family, other patients and caregivers who created a sense of community and belonging.

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2. Transplant team who created a warm and welcoming environment that made us feel safe and comfortable.

Putting it all together

Home is defined by people and the feelings that these people create.

Relocating to access transplant care is made easier by these very same things.

Thus, home is connected to the transplant journey.

So now what? What is the change?

Now that we know home is connected to the transplant journey, how will this benefit patients, caregivers and the medical community?

My goal was to make relocating to access transplant care easier for patients and caregivers.

How we will do this:

1. Transplant teams must connect patients and caregivers with each other. Having a patient/caregiver mentor or mentoring others is valuable and benefits all involved.
2. Logistical supports. Moving to a new city is stressful, especially when also dealing with a life-threatening illness. A “welcome kit” is needed to provide patients and caregivers with practical information about the new city and would include information on accommodations, public transit, location of pharmacies and grocery stores. Partnerships with services providers that support patients who must travel for medical reasons (such as

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charities and hotels) are needed to help ease the financial burden faced by patients and caregivers who must relocate.

3. Support for caregivers – being a caregiver is overwhelming. Education sessions and support groups are needed to allow caregivers to connect with other caregivers, have a safe space to share what they are going through and learn tips and techniques.
4. Create awareness – as part of my knowledge dissemination plan, I will present my research at conferences, through journal articles, and during a podcast to ensure medical professionals are aware of the challenges faced by this population and lead to changes in policy, funding, communication and collaboration.

I'm fortunate to work at the top transplant center in the country and to have the support of the transplant program these initiatives. A mentoring program that matches patients and caregivers with others who are experiencing the transplant journey has been developed and is now in place. Caregiver supports as well as logistical supports are in development and will be piloted within a specific organ program, with the goal of expanding the transplant program as a whole. And finally, by the time this video is released, I will have written journal articles, presented at conferences and my podcast interview will be released.

Conclusion

Jamie introduced me to the world of transplant. If it wasn't for him, I would have no knowledge of this field.

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Leaving home to access transplant care challenged me but also provided opportunities to learn, grow and persevere.

Hearing the stories of other patients and caregivers who relocated to access transplant care, analyzing my own journey and thinking about the definition of home, made me realize that home is not a physical structure or geographical location. It's not about where we are, but who you are with and how these people make us feel.

In the simplest terms – home really is where the heart is.