EXPERIENCES OF CARE IN NEOLIBERAL TIMES

BEING, NEGOTIATING, MENDING: EXPERIENCES OF CARE IN NEOLIBERAL TIMES

By KERI CAMERON, B.A., M.A.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy

McMaster University, April 2020

McMaster University DOCTOR OF PHILOSOPHY (2020) Hamilton, Ontario

(Geography and Earth Sciences)

TITLE: BEING, NEGOTIATING, MENDING: EXPERIENCES OF CARE IN NEOLIBERAL TIMES AUTHOR: Keri Cameron, M.A. (York University), B.A. (Ryerson University) SUPERVISOR: Professor Vera Chouinard, Ph.D. NUMBER OF PAGES: vii, 225

LAY ABSTRACT

In this study I explore care in Ontario, Canada both as a patient and as a researcher with background in disability studies and social geography. I observed care and recorded fieldnotes as a patient researcher over thirty-two months and interviewed a total of nine people who underwent hip or knee replacement surgery about their experiences of care pre and post-operatively. Two daughters of participants also took part in interviews. I explore our individual stories of care and how the broader health system helps to shape our encounters with health care workers. Government reductions in funding for care and the de-listing of services translates into poor working conditions for health care workers and insufficient care for patients. The responsibility for care is increasingly being shifted from the state to individuals. My research reveals how patients manage within this fragmented system made up of formal, informal, and private care arrangements.

ABSTRACT

The purpose of this study is to explore care in Ontario, Canada from the perspective of patients. I took on the roles of both a patient and a researcher, exploring the current state of care as a patient who has navigated the health system and as a researcher with background in disability studies and social geography. I use feminist auto/ethnographic methods, including observation and fieldnotes, journaling, memory, and notes in my patient records as data. I also conducted semi-structured in-depth interviews with seven individuals who underwent hip or knee replacement surgery and two family members who provided informal care to individuals post-operatively. I have organized data using three storylines: being patient, negotiating care, and mending fault lines. There are two layers of my analysis: our individual encounters with carers alongside our changing embodiment and the broader care relations of the system, increasingly influenced by neoliberalism. Care is increasingly informalized and commodified as austerity measures cut public financing for care and services are de-listed. Neoliberalism produces poor and precarious working conditions for nurses and personal support workers and this translates into insufficient care for patients and support for families. With care increasingly being shifted to the home and community, individuals and families are taking on more responsibility in terms of caring for family members.

ACKNOWLEDGEMENTS

I am grateful to the individuals who participated in this study. Your personal stories provide a great deal of insight into care and I am thankful for your willingness to share them with me.

Without the guidance and support of my committee this project would not have been possible. To my supervisor, Dr. Vera Chouinard, who has always encouraged me to think independently. I am fortunate to have had the opportunity to work with you and learn from you over the course of my degree. Dr. Robert Wilton, I am thankful for your detailed feedback and ongoing support and encouragement. Your comments have helped to shape my dissertation. Dr. Dorothy Pawluch, you have encouraged me to improve my writing and to think more critically. I appreciate your attention to detail and your support. Dr. Kathryn Church, thank you for your thoughtful guidance, patience, and enthusiasm. You have taught me so much, both academically and personally, and have been in my corner for more than a decade. I could not have done this without your guidance and support.

Mom and Dad, you have given up so much of your time to care for me after surgery and for my family while I worked late into the night writing. Your ongoing support and care have meant the world to me – I am so lucky to have you as my parents. Thank you for always believing in me.

A special thank you to my partner, Greg. I cannot thank you enough for your patience and for taking on so much so that I could work on this project. You have provided me with so much care and support throughout the years and you have helped to get me through some very difficult times. I could not have done this without you.

To Jesse and Dylan, my loves, my world. You have taught me so much about care and love over the past 19 months. I love you so much!

To my sister and friend, Amy, thank you for understanding me in ways no one else does – you have kept me afloat when I needed it. I always know that I can count on you for support.

Barb and JB, your encouragement has helped to fuel my determination. I am so thankful to have such loving parents-in-law.

Andrea and Sarah, thank you for your friendship and for always believing in me. I am so lucky to have you in my life. Sam, Des, Darlene, and Chelsea, thank you for your ongoing support. Your friendship is invaluable. To my friends and colleagues, Allison and Jenn, I am so grateful for your friendship and encouragement. Cathy, I could not ask for a more supportive and caring boss.

To all the amazing people who have helped to care for our family while I worked to complete this project – thank you. The care you have shown us and our children will never be forgotten.

Thank you to the families, friends, and carers who provide essential, and oftentimes invisible care. To the individuals, families, health care workers, unions, associations, and coalitions dedicated to improving care – your work is crucial, particularly in these times of austerity.

I am grateful for the Ontario Graduate Scholarship for supporting my work (2013-2014).

TABLE OF CONTENTS

INTRODUCTION

As our population ages the need for and cost of health care increase. Inflation and medical advances contribute to the rising costs of care (Block, 2018). Despite this, governments have increasingly put in place neoliberal austerity measures that cut public finances for care and shift the responsibility from the state to individuals and families (England, 2010; Forbes, Markle-Reid, Hawranik, Peacock, Kingston, Morgan, Henderson, Leipert, & Jansen, 2008; Hande, 2017; Hochschild, 2003; McGregor, 2001; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002).

In this dissertation I explore care in Ontario, Canada from the perspective of individuals who have undergone surgery and received care post-operatively. I draw from my experiences, fieldnotes, journals, and health records that I collected as a patient researcher over 32 months. I am deeply and directly informed as a patient who has navigated the health system and struggled in terms of negotiating care, and as an analytical scholar with a background in disability studies and social geography. I write from both of these perspectives. In this sense, my location as a patient researcher is complicated.

In addition to exploring my experience, I interviewed seven individuals who underwent hip or knee replacement (HKR)[1] surgery in Ontario, Canada, and two daughters of HKR participants. I value the ways that people narrate their

---

[1] I will refer to the procedure as HKR throughout this dissertation. I use this acronym because this terminology is cumbersome.

experience, using patient voices as an important component of my data. I knit our stories together, rooting myself in feminist auto/ethnographic methodology. Our collective voices shed light on how individuals and families cope with the shifting landscape of care, navigating an increasingly fragmented system made up of formal, informal, and private care arrangements.

Provinces and territories in Canada are required to have publicly funded health insurance plans that cover the cost of specific insured services under the Canada Health Act (1985). However, many health services are not covered or have been de-listed over the last few decades, as governments cut funding to health care in an attempt to balance budgets.

The Canada Health Act (1985) defines “insured health services” as those that are “medically required hospital, physician, and surgical-dental services” (p.2). This means that services falling outside of this list are not required to be funded through provincial or territorial health plans under the Canada Health Act (1985). Routine dental services and eye exams are just two of the health services not covered for all Ontarians, except under specific circumstances.

Perhaps most noteworthy among omitted medical expenses under Ontario’s Health Insurance Plan (OHIP) are prescription medications. While there are programs available to assist with medication costs for people under 24, over 65, and low-income families, many Ontarians pay out-of-pocket for medication or co-pay through private or medical insurance provided through their employers. OHIP+ provides drug coverage for some prescription medication for those 24 years of age or younger who do not have private insurance (The Government of Ontario, 2019). The Ontario Drug Benefit (ODB) program provides coverage for prescriptions for those over 65 and the Trillium Drug Benefit is available for lower-income families with high prescription costs compared to their household incomes (Government of Ontario, 2019). People eligible for ODB or Trillium make co-payments for prescriptions and pay an annual deduction based on financial need. Of those on these plans, some need to pay hundreds to thousands of dollars out-of-pocket as deductibles for medication before their benefit begins.

Austerity measures also include the de-listing of previously publicly funded care services and supports. One recent example is that in August of 2019, the Ontario Ministry of Health announced that they would be de-listing a number of services deemed “not medically necessary” in order to save the province 83 million dollars a year in public health spending (Ontario Health Coalition, 2019; Rachlis, 2019). Among these de-listed services were physical assessments prior to surgery unless deemed medically required and no longer funding home visits from physicians unless patients were considered “frail” or “housebound” (Rachlis, 2019). This shift leaves individuals in a position where they will need to pay out-of-pocket for some services.

The de-listing of services and supports has led to the growth of the private sector for these services. One example is routine eye examinations for individuals between the ages of 20 and 64, which were de-listed from OHIP in 2004. Physiotherapy treatment was partially de-listed as well and is now only covered under OHIP when certain criteria are met. Individuals must either be under 19, over 65, or have been recently discharged from hospital where they were an inpatient and they must be receiving physiotherapy for an injury related to their stay in hospital (Ministry of Health and Long-Term Care, 2017). There are even limits in place as to how many visits each patient may have from a physiotherapist in the community. The de-listing of previously covered health services helps to shape formal, informal, and private care systems.

While care is increasingly taking place in the home, public funding for formal homecare in Canada is inadequate and does not meet the needs of individuals requiring support (Forbes et al., 2008; Yakerson, 2019). The high cost of institutional care versus the lower cost of homecare, a growing number of individuals in need of care, and the availability of more advanced and efficient medical treatments also contribute to care increasingly taking place in the home (Barrett, Hale, & Butler, 2014; Gray, 2000; McDonald, McKinlay, Keeling and Levack, 2017).

There is a growing demand for formal homecare services and the number of patients, and complexity of needs, is increasing as the population ages (Forbes et al., 2008). In order to qualify for state-funded home care in Ontario individuals must contact their Local Health Integration Network (LHIN) or be referred to the LHIN by a physician (Government of Ontario, 2014). They are then assigned a case manager who assesses their needs and eligibility for services and support using a questionnaire tool, the Resident Assessment Instrument-

Home Care (RAI-HC) (Canadian Institute for Health Information, 2019). This tool is used to determine the types of services, and the number of hours of support, to which individuals are entitled. Those determined ineligible for publicly funded home care through the LHIN may be able to co-pay for support through community agencies or they may have to pay privately for care in the home (Government of Ontario, 2014).

Inadequate funding for home care services and supports translates into a shortage of nursing staff. Ontario has the lowest ratio of nurses per population in Canada: “669 RNs per 100,000 people compared with an average of 828 RNs in the rest of Canada” (Registered Nurses’ Association of Ontario, 2019). This translates into an insufficient number of nurses on shift to provide adequate care to patients (Yakerson, 2019) and an increased workload for nurses because they are under increased pressures to complete care work quickly, which makes for stressful working conditions for nurses and impacts the availability of and the quality of patient care.

In June 2019 the Conservative government in Ontario instituted austerity measures that included laying off 400 staff at the LHINs across the province in order to create efficiencies and reduce the deficit. The same administration, health care organizing, and care visits will need to be performed by less staff. Another example is the current reduction in funding for public health agencies in Ontario by 200 million dollars and the consolidation of public health units from 35 to just ten over the next two years (CBC, 2019; Thilina, 2019). These health units are focused on population health and prevention and some of their responsibilities include arranging vaccination programs, carrying out restaurant health inspections, and planning for infectious disease outbreaks. These reforms translate into an overall 27 per cent reduction in provincial health care funding across Ontario (Thilina, 2019).

Care encounters are shaped by the broader care relations of the system. Care comes up frequently in this study. I use the terms care and care encounter to refer to interactions between care providers and receivers. When I use the term care relations I am referring to the broader social organization of care. For instance, health system funding, service delivery policies, nursing protocols, and organizational rules and regulations. Care takes place within a system of care, with multiple social actors, that help to shape these encounters and to create expectations around how patients and nurses should behave (Hall & Wilton, 2017). Our stories point to the ways in which we organized care ourselves and reveal the impact of this changing landscape of care.

From ‘they’ to ‘we’

This research began as a project focused on the experiences of people undergoing HKR surgery. However, in April 2013 I was in the midst of conducting interviews for my doctoral research when I began experiencing severe pain in my tailbone region. I recognized this pain immediately because I had felt it 13 years prior to this. My tailbone felt inflamed with pressure and heat emanated from the area. In the year 2000, I underwent surgery to remove a cyst that had become infected. It took five months before I was able to return to school, and eight long months for my surgical wound to heal completely. Based on this experience, I knew I had another infection and that it was likely that I would need surgery to resolve it. I spent the next few months battling infection, going to medical appointments, undergoing imaging tests, and waiting to see a specialist. Later that summer when I met with the surgeon it was confirmed that I would need to have surgery and it was scheduled to take place in September.

I called the school frantically, wanting to speak with an administrator who might help me arrange a medical leave of absence. Having surgery would mean time away from school and work and a potentially long time healing at home post-operatively. I expected healing to take place over a few months, so I anticipated missing a semester of school and work while on medical leave. I was anxious at the thought of missing months of school and falling behind with research and writing.

Little did I know at the time that months would turn into years. After waiting five months for surgery, I would receive home nursing care for a total of 27 months for a chronic non-healing surgical wound. I would have countless infections and I would need to undergo a second surgery in spring 2015 in an attempt to close the wound. This meant that I would also need to be on medical leave from my doctoral studies for an extended period of time. This experience altered my research project and daily life significantly. Eventually I would need to seek treatment outside of the public health system in order to heal and return to school and work.

As these events unfolded, I came to understand that my own experiences of care could and should become part of the doctoral research. For this reason, I adopted auto/ethnographic methods to critically analyze my own and others' experiences of care. Autoethnography is a qualitative and systematic methodology (Chang, 2008; Frankhouser & Defenbaugh, 2017). Chang (2008) notes that autoethnography has storytelling features, but it goes beyond this by "engaging in cultural analysis and interpretation" (p.43). Autoethnographers use multiple internal and external means to collect data (Chang, 2008; Frankhouser & Defenbaugh, 2017). Internal means include observations, memory, and reflections, whereas external data include interviews and examining previous research and literature (Chang, 2008; Frankhouser & Defenbaugh, 2017). I use fieldnotes from my observations as a patient researcher, my personal journal, my medical records and electronic mail communication among the team of nurses providing my care, formal interviews with participants, informal interviews with other patients and care providers, as well as memory and reflections when interpreting data and writing. Frankhouser and Defenbaugh, (2017) note that, "This systematic investigation of weaving one's personal story with other data provides the framework for analyzing and interpreting the central story within a larger cultural context" (p.542).

The research questions that guided this study focus on how experiences of care are shaped and what it means to be a patient in the broader health system. These questions include: (1) What are patient's embodied experiences of care? (2) How do carers, both paid and unpaid, help shape experiences of care? (3) How do policies and processes, and the government and institutional bodies that govern these, help to shape care?

The focus of this study progressed as the research project changed. Stories of care relations and contesting public and private systems of care emerged. Participants and I shared stories of care while awaiting surgery and receiving care in hospital and at home post-operatively. As I received care from formal and informal carers, I journaled about my experiences. I kept a notebook with me as I sat in waiting rooms, and I wrote in my journal following encounters with care providers. My experiences became a rich source of data. I observed and recorded care during my time receiving care, in addition to interviewing participants using semi-structured open-ended interviews. I spoke with health care personnel during dressing changes and with other patients in waiting rooms and wrote about these experiences in my fieldnotes. As a researcher I had access to the health system from the position of a patient, which provided a unique opportunity to explore the health system from this perspective.

Research Contributions

This research contributes to the geography of care, disability studies, and feminist ethics of care scholarship. The care literature is vast, spanning multiple disciplines and covering a range of topics. Much of this literature has developed in response to the ‘care crisis’ (see England, 2010; Hande, 2017; Hochschild, 2003). The care crisis refers to the rising costs of care, poor working conditions for care providers, and the decreasing quality and quantity of care being provided by the state (England, 2010). Thus, this crisis is a consequence of the individualization and privatization of care, as a result of which predominantly women and other marginalized groups are responsible for providing the bulk of care.

While the care literature is expansive, there is a growing need for research seeking to understand how individuals and families manage informal and private care (Yu, Guerriere, and Coyte, 2015) in times of austerity and commodification (Power & Hall, 2018). Further to this, more attention should be given to understanding the experiences of individuals who have been underrepresented within the geography literature (Kaley, Hatton & Milligan, 2019; Power & Hall, 2018; & Wiles, 2011) and feminist ethics of care literature (Daly, 2013; Dossa, 2005; Hande, 2017; Kelly, 2016; Morris, 1995).

Geographers are increasingly exploring lived experience in geography (De Leeuw, Parkes, Morgan, Christensen, Lindsay, Mitchell-Foster, & Jozkow, 2017), however there is little critique of these accounts within the context of the political climate in which these experiences take place (Atkinson et al., 2015). There is a need for research exploring care in times of austerity, individualism, and commodification (Power and Hall, 2018)

My research focuses on experiences of care, drawing from the perspective of individuals having received care and my own voice as a patient researcher. This study contributes to the care literature because it helps us better understand the lived experience of care for individuals receiving care pre and post-operatively. My contributions to the literature are unique because I show how people try to manage the fragmented conditions of our health care system through informal and care arrangements. This research is timely and consequential given the changing landscape of care in Canada, where funding is being cut and care is increasingly becoming the responsibility of individuals and families.

Thesis Map

I have organized the thesis into six chapters following this brief introduction. In Chapter Two I explore the current care literature that is relevant to this study and discuss potential contributions this research makes to this expansive area of study. The areas of care literature I examine include: disability studies, feminist ethics of care, and geographies of care literature. Chapter Two is organized according to three sections. In the first section, I introduce and define key words and phrases used throughout this study. In part two, I review the ways in which care is understood in the care literature and outline tensions and similarities within it. In the third section, I explore research that includes the lived experience of care and the voice of the researcher. I demonstrate that the care literature is interdisciplinary, the concept of care is contested, the ethics of care is a major stream within the care literature, and that there has been a recent upsurge in studies focused on the lived experience of care within this body of literature.

I outline methodology and study design in Chapter Three. I use auto/ethnography to explore my experiences of care over the course of 32 months, spanning from the time I began receiving care pre-operatively beginning in April 2013 to when I received care post-operatively from September 2013 to January 2016 when my wound had healed completely. In addition, I interviewed nine people about care before and after HKR surgery. Seven of these participants underwent HKR and the remaining two are family members of individuals who underwent HKR.

I explore findings in Chapters Four, Five, and Six. Storylines came out of my narrative analysis. I have organized these chapters around these three storylines: being patient, negotiating care, and mending fault lines. ‘Being patient’ refers to the subject position of being patients in the health system as well as the expectation that we “be patient” as we wait for care and treatment. ‘Negotiating care’ refers to the ways in which we navigate care encounters and care relations.

In Chapter 6, which concerns the storyline of ‘mending fault lines,’ I explore the various ways that individuals and families try to repair deficiencies in the formal health system by providing informal care and support and purchasing care privately.

I have arranged each of these chapters in three analytic layers. I begin by sharing my lived experience of care, drawing from memory, journaling, fieldnotes, and my patient records. Next, I detail participant narratives that help to amplify each storyline. In the third layer of each of these chapters I evaluate these stories within the context of a complex broader care system, governed by neoliberalism, that helps to construct how care is organized and disorganized. Our stories reveal how care is arranged and how this arrangement connects to broader care relations.

My conclusions follow in Chapter Seven. I recap and discuss the significance of my research, reflecting on the findings and implications of this study. I highlight the contributions that this study makes to the care literature and suggest avenues for future research.

LITERATURE REVIEW

In this chapter I situate this study within the current care literature. The care literature is vast, with multiple bodies of text informed by various disciplines. Because the literature is expansive, I have focused my search by reviewing literature that is relevant to this particular study. I am a disability studies scholar with lived experience of care enrolled in a geography graduate program. As a result of my background in these areas and lived experience, my study is informed by disability studies, feminist ethics of care, and geographies of care. These are the areas I focus on in this literature review. I demonstrate four main points throughout this review: the care literature is interdisciplinary; the concept of care is contested; the ethics of care is a major stream within the care literature; and there has been a recent upsurge in studies focused on lived experience within this body of literature.

I have written this review in three sections. In the first section, I introduce the broader care landscape and define key words and phrases used throughout this study. In the second section, I outline the three bodies of care literature that inform this study. I examine the multiple ways in which care is imagined and understood within these literatures and outline major themes and debates within these bodies of literature that relate to and inform my research.

In the third section of this chapter, I focus attention on scholarship that explores lived experiences of care. I examine how this literature gives voice to those persons having received support or care, including the position of the researcher. I show that documenting the lived experience of care recipients is a valuable contribution to the care literature.

Part One

The Current Neoliberal Landscape of Care

A Fragmented System of Care

In this section I outline the ways in which care is organized and disorganized while defining key words that come up frequently in this study. I begin by outlining the current state of health care in Canada. Throughout this chapter, I define and trouble key terms and phrases as they surface.

Key words are facilitative because they lead into literature and help to communicate ideas, but they are also problematic in the way that they have become ideological, based on assumptions rather than certainty. In this sense, key words give shape to the literature in both helpful and troubling ways. Scholarly literature is professionally and socially constructed, relying on beliefs, assumptions, and expectations. Key words are used in conventional scholarship as truth; however, this usage gives a false sense of meaning. It is important to define key terms and phrases before diving into the literature, and note how I am using and troubling them.

One example is how I developed my literature review. While I come from a feminist disability studies perspective and contest the biomedical model, I have adopted medicalized language as a patient and researcher. I use medicalized language to search literature and adopt medical terms in various places throughout this dissertation. These words and phrases are helpful because they communicate ideas. However, they are problematic because they have become ideological in the sense that they are based on a set of beliefs. These conflict with my position as a patient researcher because they are based on the biomedical model. When I refer to myself as a patient researcher, I am recognizing my position as a patient receiving care while collecting research data.

Care takes place within the context of a complex broader care system that is partly shaped by neoliberalism. Neoliberalism is a governing structure that favours the privatization of services and free market capitalism (Kelly, 2016; Navarro, 2007; Sakellariou & Rotarou, 2017; Yakerson, 2019). It has infiltrated and reshaped our political and social landscape in Western capitalist nations. The adoption of austerity measures has limited the role of government in health and social programs, including in our health system in Canada (Sakellariou, & Rotarou, 2017) while increasing opportunities for capital accumulation (Yakerson, 2019). Austerity measures are government actions that reduce government spending and budget deficits. As austerity measures cut the public costs of care for fiscal reasons, care becomes an extension of familial responsibilities and takes place increasingly in the home[2] (England, 2010; Milligan & Power, 2009;

---

[2] The home is a place of residence and may include personal residences, assisted living facilities, long-term care facilities, group homes, and shelters.

Power & Hall, 2018; Williams, 2002). In this sense, care is individualized while the onus of care is placed on individuals. Individualism refers to the responsibility of health and care being increasingly placed on individuals and families and shifting away from the public health system (England, 2010; McGregor, 2001; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002).

When I refer to the “health care system,” I do not do so with the intention of implying that care in Canada is well organized or that it takes place within a completely publicly funded network of care. Instead, I use this term to refer to what is available: public, private, third sector[3], and informal care arrangements make up a system of fragmented care. The responsibility to organize care has shifted away from the state and onto individuals and families through informal care arrangements or care purchased privately. We need informal and private care arrangements to fill in the gaps in our formal care arrangements. Thus, it is only a health ‘system’ because of informal, private, and third sector care arrangements. While Canadians understand health care as a publicly funded and universal system of care, increasingly care is informalized and privatized in Canada.

Informalization refers to the increasingly precarious nature of care work. As governments have cut financing for care, they have reduced the number of formal care providers (Power & Hall, 2018; Yakerson, 2019), and formal care

---

[3] The third sector refers to voluntary and community organizations. This category includes charity organizations as well as community groups.

workers are placed in more precarious positions of employment (Zeytinoglu, Denton, Plenderleith, & Chowhan, 2015). The onus of care is also increasingly being placed on individuals and families through privatization (England, 2010; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002).

Privatization takes place in two ways: care is privatized in the form of informal, unpaid care provided by family members and friends (England, 2010; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002) and in the form of market-based solutions to care (Forbes et al., 2008; Yakerson, 2019). Market-based solutions include private care, supports, and devices that are purchased out-of-pocket by individuals and families. In this sense, care becomes commodified within a market-based system when health services and medical equipment are transformed into something that can be purchased privately and regarded merely as commodities (Cox, 2013).

Care: What is it? Who says so?

Care is a central theme in this study. The care literature is particularly difficult to map because care is complex; it comes in many forms and takes place in varying sites. Care can come in the form of formal (paid) and informal (unpaid) care. This means that some people providing care have formal credentials like nursing degrees and are paid when providing care, whereas informal carers do not have formal care-related education and are not paid for the care they provide. Informal care might be provided by family members and friends or take place through a network of volunteers. Individuals might pay for care through private channels. Care takes place within institutional settings as well as within the home or community. Care might take place in the community within the workplace or during travel.

Care is also taken up locally as well as globally within the literature. One way is through the growing interest in medical tourism. Seeking medical, surgical and/or dental treatment outside of an individual's home country is termed medical tourism within the academic literature (see Connell, 2006; Fetscherin & Stephano, 2016; Hanefeld, Horsfall, Lundt & Smith, 2013). The care literature reflects these complexities with areas of research that cover these various circumstances.

Care can be understood practically as well as relationally (Grant et al., 2004; Kelly, 2016; Milligan & Wiles, 2010; Tronto, 1993). Care does not just refer to care work that is performed. Care takes place within socio-political conditions that are influenced by neoliberalism and increasing commodification. I understand care as connected to how people relate to one another, history, and the broader neoliberal landscape.

Care can be understood differently in four areas of the literature: social policy, health care systems, care work organization, and the social model of care (Daly, 2013). While this is not an exhaustive list, these categorizations are helpful because they provide various perspectives for analysis and open up opportunities to broaden the concept of care (Day, 2013).

Within the social policy framework, care is understood as the private, personal responsibility of individuals and families (Barnes, 2012). In austere times and where care is increasingly taking place in the home, how individuals and families cope with this and how austerity impacts care are important considerations.

Within the health care system, care is conceptualized in relation to the managing of bodies and illnesses. Social forces that impact health are often neglected within this model (Day, 2013; Raphael, 2000). Social forces might include environment, family status, and socio-economic status. An understanding of the ways in which care is conceptualized in the health system and by health care workers is crucial because it helps to explain how and why care is constructed the way it is by health professionals.

The conceptualization of care in care work organizations focuses on the application of market principles to the organization of care. Care in this model is quantified and measured. Care is organized and services are allocated based on quantified and measured needs.

Finally, the social model of care is focused on care encounters (see Neysmith, 1991). Here, care is viewed as a social process, with a focus on how encounters are developed or produced. Caring is considered a way of relating to others, rather than as an activity (McEwen & Goodman, 2010). Care encounters are connected to the broader neoliberal landscape of care and the system, made up of public, private, and informal care networks that enforce the type of encounters we have with care providers.

Tronto (1993) outlines four phases of caregiving: caring about, taking care of, care giving, and care receiving. As Barnes (2012) suggests, “An understanding of care as practical, political and moral provides a robust and critical basis on which to build relationships in diverse contexts” (p. 7). All individuals require and provide some form of care over the life course (Barnes, 2012). Barnes (2012) uses the example of an infant in need of care not just for the basic necessities of life, but also in order to grow and develop into a contributing member of society. As humans grow they continue to need care in various forms and instances throughout their life course. During periods of illness or following surgery, for instance, individuals might be in need of care (Barnes, 2012; Kittay 1999). Kittay (2011) states that care can be a virtue, an attitude, or labour. Care takes multiples forms, has various meanings ascribed to it, and can be understood in different ways. The literature reflects these complexities.

In the section that follows, I engage with the care literature from disability studies, feminist scholarship, and health and social geography, noting how care is conceptualized in each of these fields. These care literatures reflect the intricacies of the concept and they are therefore difficult to map. While I engage in these fields separately I also recognize that there is overlap and intersection among them. One example of such overlap and intersection is that many disability studies scholars are feminists, and some feminist scholars are disabled or apply disability studies theory (see Garland-Thomson, 2005; Kittay, 2011; Morris, 1993). Similarly, geographic work draws from both feminist ethics of care scholarship and the disability studies literature. Although there is overlap among these disciplines, I have organized these sections separately, making note of tensions and similarities throughout.

Part Two

Scholarly Literature on Care: An Interdisciplinary Body of Knowledge

Disability Studies

The first body of literature I focus on is the disability studies literature. Within disability studies, disability is understood as a social relation rather than individual impairment. The social model of disability makes a distinction between impairment/individual limitations and social contributors to disablement (Gleeson, 1999; Hall & Wilton, 2017). The Disabled Peoples' International's (1982) definitions of impairment and disability provide clarity on the social model. Impairment refers to "functional limitation within the individual" (as cited in Oliver, 1990, p. 31), while disability refers to "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (as cited in Oliver, 1990, p. 31). Thus, within the social model struggles to negotiate barriers that prevent people from being fully included in everyday life are considered (Freund, 2001; Rioux & Daly, 2006;

Prince, 2009). Stairs and heavy doors are examples of physical barriers. These can pose obstacles for people. Social barriers refer to the attitudes and actions of others. Thus, the social model contrasts with biomedical constructions of disability or illness as barriers to inclusion (Freund, 200; Prince, 2009; Rioux & Daly, 2006).

Biomedical interpretations understand and construct disability as an individual impairment that impedes an individual from participating in activities of daily life (Prince, 2009; Rioux & Daly, 2006). The built environment, attitudes, beliefs, policies, practices, and social values that act as obstacles to participation are not considered in the biomedical model of disability. I have chosen to use 'disabled person' throughout this dissertation because it is the term used most often by advocates and individuals in disability studies, as well as being in line with social model theory. The term *disabled person* is used to draw attention to the ways in which individuals are 'disabled by' barriers, rather than suggesting impairment is the only contributor to disabling experience (Morris, 2001). Disability activists and studies scholars promote the use of identity-first language, challenging the use of person-first language (e.g. people with disabilities) (Dunn, & Andrews, 2015). The key criticism they make is that person-first language separates the person from their disability and may promote ideology that frames disability as undesirable (Dunn & Andrews, 2015). Hence, the term 'disabled person' recognizes disability as a cultural identity.

While impairment has historically been rejected as a contributor to disablement in disability studies, the field's theoretical foundations have evolved over the years, establishing an understanding of disability as embodied. Meeks (1986) describes embodiment as something fluid and subjective, while also biological and political. Embodiment refers to our biological and physical bodies in place. We embody various roles depending on our history, encounters with other social actors, and places we frequent. One might embody the role of a parent, cook, nurturer, or carer at home with family, and the role of an authoritarian, diligent, and strict CEO in the workplace during the day. That same person might then embody the role of the comedian with friends. Roles change as our circumstances change and as the landscape of our lives alters. In the context of post-operative care we may embody the role of a patient receiving home care service or the role of an advocate. We may take on the role of carer to ourselves and others. Thus, embodiment is fluid, ever-changing, and produced by our environment, the events of our lives, and encounters with others.

Within disability studies, Freund (2001) promotes a socio-materialist approach to disability. Within this approach, minds and bodies are situated in space, taking impairment and space into account. An individual's experience of care is shaped by the places they inhabit, the processes of inclusion/exclusion and enablement/disablement that operate within these places, and their embodied impairment. The physical layout of people's home and community, and their relationships with family, friends, and care providers, influence their experiences of care, in combination with their experiences of pain and mobility. A single-level home or a home accessible for an individual who uses a mobility aid could be more easily accessed by a person using a walker than a multiple-level home with stairs and other physical barriers.

The concept of care has long been contested in disability studies because it is traditionally conceptualized as a form of dependency or oppression (Daly, 2013; Davis, 1995; Kelly, 2016; Linton, 1998). The person receiving care is often constructed as dependent, failing to recognize interdependence in the care relationship (for instance, see Morris, 1997). Morris writes:

> Empowerment means choice and control; it means that someone has the power to exert choice and therefore maximize control in their lives (always recognizing that there are limits to how much control any of us have over what happens in our lives). Care—in the second half of the twentieth century—has come to mean not caring about someone but caring for in the sense of taking responsibility for. People who are said to need caring for are assumed to be unable to exert choice and control. One cannot, therefore, have care and empowerment, for it is the ideology and the practice of caring which has led to the perception of disabled people as powerless. (Morris, 1997, p.1)

This conception of care continues today. Kelly (2016) reports that disabled people in her study reject the use of the term ‘care’ because of the long history of oppressive and paternalistic practices associated with care relations.[4] This understanding stems from historical care encounters encompassing a denial of

---

[4] Participants in Kelly’s (2016) study were on Direct Funding. Direct Funding is a program in Ontario that enables people to self-manage their own support. They are in charge of hiring, training, organizing, and paying employees. Public funds to pay attendants are provided through the Centre for Independent Living in Toronto (CILT).

agency and choice, abuse and coercion of individuals, and an unequal balance of power in care encounters. Historically, institutions were sites of care for disabled people who endured sterilization, abuse, and institutionalization in the name of care (Kelly, 2016).

Disability studies scholars explore the meaning of care as disempowering. Morris (2004) argues that community care is disempowering because the legislative framework governing community care, and attitudes about disability and independence, creates barriers and undermine Independent Living. She (2004) reports that care workers' assumptions about 'capacity' and concerns about 'risk' in care are major barriers to independent living and access to direct payment programs[5]. Barriers such as these also create geographical variations in access to health care supports.

Disabled people continue to experience and reject systematic marginalization and medicalization in health care (Hande, 2017; Kelly, 2016). One example of marginalization is access to health care clinics in Ontario. These clinics are not required to be accessible for those using mobility devices. For example, a specialist's office can have stairs and is not required to have an accessible entrance. This means that some individuals do not have access to the same health care clinics as those who do not use mobility devices. Thomas (2001b) investigates disabled women's experiences within health care, focusing

---

[5] Direct payment programs are programs that provide funding to disabled people to manage their attendant service.

on the practices and attitudes of physicians. Thomas uses narratives and interviews with seventeen disabled women, focusing on their reproductive experiences in health care. Her research reveals that disabled women experience oppression in health care due to patriarchy and disablism.

Disability studies scholars bring awareness to the fact that disabled people have been and continue to be at risk of abuse in the context of care settings and encounters (Kelly, 2016; Morris, 1995; Saxton et al. 2001). Saxton et al. (2001) suggest that abuse can be blatant and subtle in care encounters. It might include control or manipulation. Thus, care has a long history of oppression and abuse, which are disguised as care.

The ideas behind the Independent Living Movement are that disabled people should have opportunities for choice and control, disabled people should have control of the support received, and the concept of independence should be challenged (Morris, 1995; Morris, 2004). Disability studies has drawn attention to the emancipatory potential of this movement. Morris (1993) notes that there are four assumptions on which the Independent Living Movement is based:

> that all human life is of value; that anyone, whatever their impairment, is capable of exerting choices; that people disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives; that disabled people have the right to participate fully in society. (p. 21)

Independent Living scholarship, as with the broader disability studies literature, approaches care critically given the long history of oppression, institutionalization, and abuse faced by disabled people (Hande, 2017; Kelly, 2016; Kröger, 2009).

Care is often equated with enforced dependency; disabled people are often conceptualized as solely dependent and in need of care, rather than as independent or interdependent individuals (Kröger, 2009; Morris, 2001). Many individuals in the Independent Living Movement argue that they are not in need of "care," but rather need assistance in order to live independent lives. For these reasons, the use of the term 'care' is often problematized or rejected among disability activists and scholars (Morris, 2001). The terms 'help' or 'support' have been suggested to replace care in order to move away from the negative implications of care (see Finklestein, 1998; Shakespeare, 2000).

While the term 'care' is rejected by many disability studies scholars, it is recognized that the concept of care may capture instances where people need intimate personal care or an individual requires health care during times of illness (Kelly, 2016; Morris, 2001). When an individual is hospitalized for illness or undergoes an operation, for instance, they require care. Care may also be necessary in intimate encounters where a particular level of personal assistance is provided (Kelly, 2016). When someone needs assistance in the washroom or with bathing, for example, the individual receiving support is in a vulnerable position or may be exposed (Kelly, 2016). In situations like these, a level of care would be required of care providers that they be discreet and supportive. In the next section, I discuss the feminist ethics of care scholarship.

Feminist Ethics of Care

Care is a significant focus of feminist scholars. Second wave feminists were particularly concerned with the invisible work of women. Much of this research was focused on the ways in which care and work were defined in patriarchal traditional scholarship (see Neysmith & Aronson, 1997). Care was not viewed as work, but rather as part of the everyday responsibilities of women. Feminists worked to change this perspective, and for care work to be valued. Feminists demonstrated that care work is often devalued because much of this work has traditionally fallen on women. Further to this, care work is often racialized.

Feminist scholarship on care provides a relational ethical theory (Noddings, 2012). From this perspective, caring has a highly valued, central role within society. Feminist ethics of care scholars are interested in care relations (Cox, 2010; Lawson, 2007). The commonly held core assumptions of an ethics of care include the notions that “humans are interdependent and hold responsibilities to others; that caring is the highest ideal; and that all people are considered to be of moral worth” (Daly, 2013, p. 36). An ethics of care suggests that in order to enable human flourishing, we need to focus on the specifics of daily interactions, recognizing the need for care giving and receiving (Barnes, 2012). Morris (2001) notes that the feminist ethics of care “is based on a recognition of interdependence, relationships, and responsibilities, and …criticizes notions of autonomy, independence, and individual rights as being too much based on a masculine view of people as separate from each other” (p. 13).

The intention of feminist ethics of care research is to understand the meaning and impact of care. It focuses on care encounters and care-giving work (Kröger, 2009). There have been two waves of feminist ethics of care scholarship (Daly, 2013). The first wave of research assumed that there was a naturalness and obligation to do care work for women (see Noddings, 1984). Noddings (1984) explicitly refers to caring as feminine in her book, *Caring: A Feminine Approach to Ethics and Moral Education*. Within early ethics of care literature, care was not understood as an interdependent relationship (Kelly, 2016). Gilligan (1982) describes care as responding to and taking care of the needs of others. Much of this early feminist work came from the perspective of the care provider.

In more recent years, feminist ethics of care research has begun to focus on anti-oppressive and critical areas (Daly, 2013; Hande, 2017). Researchers in this area have begun to include critical theory in their work, consider intersectionality, and focus on the experiences of those receiving care. The second wave of research is termed the political ethics of care scholarship (see Tronto and Fisher, 1990). This area of research challenged earlier assumptions about a naturalness to care work and focused on social factors and political action (Brannelly, 2018; Daly, 2013). The purpose of political ethics of care research is to highlight marginalization and address inequality (Brannelly, 2018).

Brannelly (2018) explains that as participatory methodologies[6] have become more in demand, the feminist ethics of care field has evolved. This research has been developed in response to neoliberalism. The idea that care is central to the construction of a functioning society emerged and care began to be understood as a source of empowerment and fulfillment for women (see Gillian, 2013). One key attribute of the political ethics of care is that care is political with a focus on social justice (Brannelly, 2018). Brannelly (2018) explains that participatory research, with the intention to promote positive change, is advocated for among feminist ethics of care scholars. Counter to neoliberal constructions of care as an individual responsibility, the idea that we are interdependent, and have the capacity and responsibility to care and be cared for, emerged (Barnes, 2012; Brannelly, 2018; Williams, 2001). Thus, understanding power and difference is important for a political ethics of care. Research focuses on the relational aspects of caring as well as the broader political landscape.

Care is considered a moral action that centres on interpersonal encounters. According to Tronto's (1993) well-known definition, care is "a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live as well as possible" (p. 103). There are four principles of an integrity of care: attentiveness, responsibility, competence, and

---

[6] Participatory research is research that is conceptualized and disseminated through a partnership between researchers and participants. This partnership includes developing methods, collecting data, and analysis.

responsiveness (Tronto, 1993). Attentiveness refers to the understanding that there is a need for care and to the posture of being attentive to the needs of others (Barnes, 2012). Care cannot be given unless there is an awareness that there is a need for care (Barnes, 2012; Tronto, 1993). This also means being attentive to the unique needs and circumstances of others. Barnes (2012) provides the example of forced migrants. If the experience of this group is ignored and the members cannot access insured health care services, then there is a lack of attentiveness to their needs for care. There is inattentiveness to individuals but also inattentiveness to groups who may be in need of care.

Responsibility refers to the need for action in response to needs. Responsibility does not mean an obligation to care; instead it refers to a complex set of cultural practices. Within many cultures, adult children are often responsible for caring for aging parents, for instance (Barnes, 2012). This might mean providing care themselves, or it might mean ensuring formal long-term care is organized. This care varies based on the needs of children and parents, geography, and feasibility, and is not an obligation but an understanding of interdependence and perhaps reciprocity for parents providing care for children as infants. At the same time, ethics of care scholars often argue that the state should be responsible for caring for its citizens (Barnes, 2012).

Feminist ethics of care scholars note that in order for care to have been received it must be given competently (Barnes, 2012; Tronto, 1993). Responsiveness is closely tied to competence. Barnes (2012) notes that we must be responsive to particular needs for care in order to be competent. If an individual with a mobility issue is in hospital and needs assistance with meals, for instance, but it is not recognized that the individual needs support in order to eat and be nourished, competent care cannot be provided. Hospital staff would need to be attentive and respond to these needs in order for care to be provided.

Within the ethics of care scholarship, Gilligan (2003) makes an important distinction between caring-for and caring-about. She explains that caring-for is when an individual recognizes and responds to the need for care. Caring-about differs because an individual can care-about a group of people, but not act on the need for care. She uses the example of caring-about individuals who are struggling for food in developing countries. An individual might care-about the conditions in which these people live, but does not, or does not have the means to, provide care-for this group of people. She explains that organizations and states might not have the means to care-for individuals directly, but they can create environments where caring-for takes place.

Feminist care scholars generally frame care as a gendered form of work (see Bond, Punnett, Pyle, Cazeca, & Cooperman, 2004, Morris, 2001; Tumolva & Tomeldan, 2004). These scholars are critical of the gendered nature of care work where care is often racialized, devalued, and disproportionately carried out by women. Tumlova and Tomeldan (2004) explore Canada’s Live-in Caregiver Program, sharing an example of a woman from the Philippines working as a live-in caregiver through the program. They explain that those who work within the program often endure many long unpaid hours and violations of their privacy, as well as experience sexual abuse and harassment and isolation.

The ethics of care is expansive and continues to advance through the use of participatory methods. Next, I move on to examine geographies of care.

Social Geographies: "Care-ful"

Finally, the geographies of care literature, which is informed by feminist ethics of care and disability studies, examines the significance of care in place (Milligan & Power, 2009). Place can be understood as a venue that is a defined space and to which people have attached emotional and personal feelings (Agnew, 1987). Place can be defined with walls or streets. A community centre is considered a place. New York, the park, and my home are also places. Thus, place is not simply a physically defined space, but rather a socially constructed area within space and time that people assign meaning to, have feelings about, and is defined for a specific purpose.

Increasingly, geographers are thinking about space relationally rather than as static. Space is understood as being produced, unmade, and remade through diverse relationships and interactions (Hall & Wilton, 2017; Massey, 2005; Murdock, 2006). Relationships and encounters between and amongst patients and health care workers help to shape space. The making and unmaking of space is also impacted by politics. For instance, neoliberal austerity measures have an effect on the assistive devices we will have access to and the time care workers will have to provide support. In this sense, space is made and unmade through various relations.

Milligan and Wiles (2010) refer to geographies of care that are informed by a feminist ethics of care as care-ful geographies. Geographers consider care to be embodied, emotional, and relational (Power & Hall, 2018; Wiles 2011). Within this perspective, bodies, objects, and space are constantly involved in shifting relations and connections (Hall & Wilton, 2017). As Atkinson et al. (2015) state, "Health…is conceptualized [in geography] as something that is produced through the relations between bodies rather than as something that a body is or is not" (p. 77). This approach emphasizes the ways in which health, care, space, illness, and disability are constructed in relation to one another. Care is connected to people, history, encounters with others, and bodies, while the body is interconnected with spaces, people, and history. Within care-ful geographies, care must be approached from the position that individuals are interdependent and care is relational, considering how care is influenced by multiple forces and is multidirectional (Milligan & Wiles, 2010). Milligan and Wiles (2010) suggest that care is multidirectional in the following ways:

> (1) care often involves networks rather than dyads; (2) even within dyadic relationships different kinds of care, including physical and affective, are frequently exchanged; (3) care can be expressed as delayed or extended reciprocity (e.g., care for an ageing parent may reflect reciprocity for care received in childhood); and (4) care providers frequently derive significant benefits such as a new perspective, a sense of pride or satisfaction, learning new skills or developing a vocation, a sense of power, or alleviation of guilt.

Thus, care can be understood as being influenced by multiple forces, including health care organizations, care workers, and families. Care and space are understood relationally in the sense that they are influenced by broader relations such as organizational policy, health care funding, and nursing protocols. People provide and receive care work within a larger system of care.

Geographers explore care from a range of scales and in a variety of settings, investigating the changing geographies of care (Cox, 2013). They have observed care in the home, within communities, as well as on a global scale (Power & Hall, 2018). Power and Hall (2018) explain that care takes place within socio-political conditions that are increasingly influenced by neoliberalism and commodification. Socio-political conditions refer to the social and political circumstances in which healthcare takes place—for example, the social belief that individuals should be responsible for their own health. These ideas are partly shaped by, and reinforced within, a neoliberal political economy that cuts public funding and increases the need for informal and private care arrangements. These forces help to shape the ways in which care is constructed and takes place. Geographies of care develop in response to the shifting social landscape and the political circumstances surrounding care (Milligan & Power, 2009; Power & Hall, 2018).

Geographers have been particularly interested in how the shifting neoliberal landscape and austerity measures help to shape support provisions (Milligan & Power, 2009; Power & Hall, 2018). The neoliberal care landscape has shifted care to the home and increased the responsibility of care to individuals and families (England, 2010; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002). This informal, community-based care is then viewed as an extension of familial responsibilities, rather than the responsibility of the state (Milligan & Power, 2009). This care is usually done by family or friends. Formal care, on the other hand, is paid and voluntary care (Thomas, 2007).

Geographers have called for critical scholarship to understand how neoliberal austerity measures have impacted care and care relations (Power & Hall, 2018). According to Hande and Kelly (2015), neoliberal austerity measures disproportionately impact how disabled and ill people access services. In response, austerity measures have been a driving force for new disability activism and care politics. Whiteside (2009; 2011) explains that the healthcare system in Canada is moving towards a two-tiered system through access to medical tourism, subcontracting, and fundraising efforts.

Alongside informalization, geographers have been concerned with the commoditization of care within the current political landscape (Cox, 2013). Cox (2013) explains that with the increasing commoditization of care, care is understood as a transaction rather than as a social relation. One way that care becomes a product of the market is with direct pay programs, such as the Direct Funding program in Ontario (Cox, 2013). Care in the home becomes commoditized as individuals purchase care services. This results in a new and different set of care workers through family members and migrants, which means that commoditized care can become entangled in global networks (Cox, 2013).

Henderson and Petersen (2002) suggest that there are a number of implications for health as a commodity and product. It constructs those who use health care as consumers of care and raises questions regarding out-of-pocket expenses and expectations that health care users play a more active role in maintaining health.

While geographies of care is a growing area of interest in geography, there are areas that are in need of further development. The use of lived experience of receiving care has grown in geography (De Leeuw, Parkes, Morgan, Christensen, Lindsay, Mitchell-Foster, & Jozkow, 2017), however, accounts are predominantly positive lacking a more critical perspective (Atkinson et al., 2015). Further to this, Yu, Guerriere, and Coyte (2015) call for more research that explores how care is managed informally and privately by individuals and families.

In this section I have illustrated that the geographies of care literature is informed both by disability studies and feminist ethics of care scholarship. The care literature is a growing and interdisciplinary area of study. I explore tensions and similarities among these three disciplines in the section that follows.

Tensions and Similarities in the Literature

There are multiple areas of difference within the care literature. The first line of tension is in defining care. The ways in which care is understood are highly contested within and across the current care literatures. There is tension among disability and feminist scholars in defining care (Hande & Kelly, 2015; Hande, 2017; Kelly, 2016; Milligan and Wiles, 2010). Care is clearly contested by disability studies theorists while it is embraced among feminist scholars. Morris (2001) explains that when conceptualizing care in disability studies, independence is reinterpreted as having choice and control in decision making and the assistance received. By contrast, the feminist ethics of care scholarship is based on a recognition of interdependence and encounters, and the focus is on gendered forms of work. Disability scholars and activists reject a language of care, instead opting for needing personal assistance or attendant service and using terms such as ‘help’ or ‘support.’ However, Barnes (2012), a feminist ethics of care scholar, argues that help and support do not adequately describe care. She writes:

> none [of these terms] carries the ethical resonance that is necessary as a basis on which social policies capable of delivering justice and well-being in situations of dependence and vulnerability can be built. Nor do they embody an understanding of the emotional, social and relational nature of human interdependencies that are necessary to ensuring practices that respect not only the recipients of care, but also both paid and unpaid care givers and the relationships between them (p. 5).

Kelly (2016) argues that *accessible care* might bridge the divide among the care literatures. Kelly suggests that by understanding care as a tension within the literature, with various definitions, we can use care to connect feminist and disability literature. Care is understood as a form of oppression, a relation, a virtue, or attitude. This takes into account the various understandings of care within the literature, rather than employing merely one definition.

While disability studies scholars consider oppression and abuse facing disabled people in care relationships, feminist ethics of care scholars focus on the abuse of workers. Disability studies scholars have been criticized by feminist scholars for coming up short of exploring gendered, racialized, and oppressive forms of work, as well as the possibility of abuse of employees (Kelly, 2016). Individuals who provide attendant service might be treated poorly by their employers, may not get breaks to which they are entitled, or may complete tasks outside of the scope of their job description. While abuse is documented for those receiving support within disability studies literature, the literature has been criticized, by feminist scholars, for failing to consider the abuse and oppression of those providing attendant service. Attendants may also need to work for various employers, going to multiple homes throughout the day, in order to make ends meet. The experiences of attendants or those who provide care or support are scarce in the disability studies literature (Kelly, 2016).

Geographers have also been criticized for excluding a care provider perspective. Connell and Walton-Roberts (2016) explain that geographers rarely include the perspective of care providers in research. They suggest a deeper engagement with feminist and labour geographies by examining the role of health care workers in order to address this gap.

Disability studies scholars have found fault with feminist care scholars for continuing to exclude the voices of those receiving support or care from the literature, as well as ignoring disability altogether (Daly, 2013; Dossa, 2005; Hande, 2017; Kelly, 2016; Morris, 1995). Thomas (2001a) argues that feminists have long ignored the issue of disability. Feminists care scholars have also been criticized for constructing disabled and older people as dependent or burdens of care, not allowing space for the subjective experience of those receiving support (Morris, 1995). Instead, feminist literature focuses on the exploitative nature of gendered care work (Daly 2013; Hande, 2017; Kelly, 2016). Hande (2017) notes that some feminist disability scholars, however, have studied gendered and embodied dimensions of care (see Morris, 1995; Thomas, 2001a). Morris (1995), for instance, explored whether community care policies have particular implications for disabled women.

While there are debates present, there are also similarities across the care literature. One major element is that the feminist ethics of care is a major stream within the care literature. It is applied in disability studies and the geography of care. Within disability studies, some scholars use a feminist lens when investigating care. Garland-Thompson (2005) explains that feminist disability studies challenges biomedical constructions of disability as flaw in the same way that feminism problematizes the idea that femaleness is a form of physical or mental shortfall. Wendell (1997) addresses how disability is defined, who is considered disabled, and how attitudes contribute to stigma. She employs established concepts in feminist literature such as the politics of language (see Cameron, 1995) and othering (see Beauvoir, 1949).

Another similarity is that much of the care literature has emerged in response to a ‘care crisis’ (see England 2010; Hande, 2017; Hochschild, 2003). Power and Hall (2018) explain that care support is both individually focused and market-driven. Individuals access care through multiple channels: public, private, third sector, and informal support. This shift has changed the meaning and relationships associated with caring. Some individuals are forced to rely on family to provide support following surgery, for instance. Care literatures examine how neoliberal programs aim to shift the responsibility of care from the state to individuals and families (DeFalco, 2016). One example includes Ontario’s Aging at Home Strategy (2007), which encourages people to age at home (DeFalco, 2016). DeFalco (2016) explains that while most people would choose to be at home while they age, the policy actively encourages individuals to do so in order to shift the responsibility of care away from the state, with negative consequences for both care providers and recipients.

In addition to the onus of care being shifted to individuals, care is being increasingly commodified (Cox, 2013). Cox (2013) explains that care is commodified when it becomes a product of the market. For instance, Direct Funding, and other direct pay programs, shift care to the market, where individuals purchase support services rather than receive care through the public system. This commodification of formal care helps to shift the onus of care from public to private spheres. Geographies of care, disability studies, and feminist studies have explored the commodification of care. Hande (2017) examines disability organizing in North America from a critical disability studies perspective. She explains that the increase in attention to care within radical and community-based activism is in response to neoliberalism. She uses a relational/reflexive method to investigate how activists, organizers, and politicized care workers develop a disability consciousness. She notes that conceptualizing care within the context of relations of austerity and capitalization also means to understand the body as in need of care. Geographer Cox (2013) explores the commodification of care across the current neoliberal care landscape. She notes that care is commoditized in market-based relationships, which blurs the boundaries between public and private. At the same time, her analysis exposes the political nature of this divide, revealing gender, racial, and class inequalities in care. Thus, the individualization of care under neoliberal policy frameworks is a major theme in the current care literature.

Within this section, I have demonstrated that the care literature is interdisciplinary, spanning across various disciplines. I have illustrated that the feminist ethics of care is a major stream across the areas of care literature examined, and that among these bodies of literature, care is contested. In the next section, I discuss the recent upsurge of care literature.

Part Three

Lived Experience of Care

Personal Stories

With the care literature outlined, and major themes and debates sketched, I move on to examine scholarship that includes an explicit focus on lived experience of care and support,[7] as such experience provides the central focus of my thesis. Lived experience is an important element of the care literature and there has been a recent upsurge of studies drawing on the subjective voice. In this section, I draw out the value of lived experience, continuing to focus on the three bodies of literature examined in this review. I also consider literature that includes the voice of the researcher.

Lived experience refers to the subjective voice in research. This might include the voice and experience of participants or of the researcher. Much of this work comes from narrative, memoirs, autobiography, and autoethnography. Disability studies, feminist ethics of care, and geographies of care scholars advocate for the inclusion of this lived experiential knowledge and for the inclusion of narratives that were previously neglected within research (Butz and Besio, 2004; Morris, 1992; Morris, 2001; Moss, 2001; Perreault, 1995).

---

[7] I refer to 'support' to recognize that many individuals reject the use of the term 'care.' Instead they may opt to refer to themselves as self-managers who have support to live independently.

Morris (2001) asserts that there is value in subjectivity within research. The subjective voice helps readers imagine that they have lived this experience or that they could in the future. Atkinson and Delamont (2006) note that

> narratives are produced and performed in accordance with socially shared conventions, they are embedded in social encounters, they are part and parcel of everyday work; they are amongst the ways in which social organizations and institutions are constituted; they are productive of individual and collective identities; they are constituent features of rituals and ceremonies; they express authority and expertise; they display rhetorical and other aesthetic skills. (Atkinson & Delamont, 2006, p. xxi)

Thus, narratives are constructed in and derived from various encounters with others and help to reveal care relations. Atkinson and Rubinelli (2012) suggest that narrative methodologies reveal health care needs and potential for improvement, as well as uncover the politics of ill-health experiences. Narratives provide insight into how care is experienced and represented, and how care is understood. They help to reveal how policies, organizations, and institutions that govern the organization of care construct experiences of care. Lived experience is a growing thread across multiple literatures.

Within disability studies, including the voices of disabled people is of central concern. “Nothing about us without us,” a common phrase among disability activists, insists that we must always include disabled people in decision making and research; it is oppressive not to do so (Charlton, 1998; Lezzoni, 2012). The richness and complexity of experiences of disabled people continue to be overlooked and underrepresented (Hansen, Hanes & Driedger, 2018).

Dossa (2005) takes a critical approach by exploring intersectionality through the lived experience of a disabled Muslim woman with polio. The inclusion of lived experience provides an embodied understanding of what life might be like for such a woman. This study reveals her everyday life, uncovering race, gender, and disability constructs. Dossa (2005) notes that the lived experience in her study is used as a foundation to explore the political, social, and economic conditions in which these experiences take place.

Much of the field of disability studies was created around personal accounts and narratives (see Frank, 2000; Kittay, 2011; Murphy, 1987). Frank (2000) uses ethnography to consider her relationship with Diane DeVries, a disabled woman who was born without arms or legs. Frank (2000) documents their relationship, which developed over twenty years, reflecting on their encounters throughout, as well as her initial view of DeVries. She explores cultural representations of disability and disabled women. She continues to reflect on such representations throughout the book, exploring her own invisible disabilities. She reflects upon how her relationship with DeVries altered her understanding of disability and life more generally. Kittay (2011) reflects upon her experience of care and disability with her daughter, who has cerebral palsy and does not communicate verbally. She explains that her daughter requires care and that this care is indispensable. Lived experience helps us to understand care from the perspectives of individuals receiving or providing care.

Lived experience continues to be at the forefront of disability studies. Kelly (2016) studies the experiences of disabled people who elect to be ‘self-managers’ hiring attendants and directing their own attendant support through Ontario’s Direct Funding Program. While many of those receiving support through the program do not consider the program a health care support, the program is funded by the Ministry of Health and Long-Term Care, and thus falls under the umbrella of health care services in Ontario. First-person accounts of support are shared throughout this work while Kelly reflects on her relationship to someone in the program. While lived experience is an important element of disability studies scholarship, I was not able to find personal accounts in the context of post-surgical care.

There is also a rich literature drawing on lived experience within the feminist ethics of care field. Feminists advocate for the inclusion of lived experience in research because it includes the voices of people who have been previously neglected in the research (Butz & Besio, 2004; Morris, 1992; Moss, 2001; Perreault, 1995). Research, however, as noted in the first section of this chapter, has been criticized for focusing more often on care providers’ perspectives and leaving disabled people and care recipients out of the research. While the focus is most often on health care providers’ experience, some scholars have researched the experiences of those receiving care or support. Pascal and Endacott (2010) use phenomenological methods to reveal patients’ experience and challenges associated with cancer diagnosis. Specifically, they report ethical and existential challenges regarding cancer diagnosis and survival from the perspective of people who have been diagnosed with cancer. Their findings have implications for the practice, education and professional development of care providers. Pascal (2006) reveals patient lived experience of surviving cancer. The purpose of the study was to contribute to literature exploring embodiment, emotions, and spirituality from the perspective of cancer survivors. They discovered that meaning making is both a temporal and relational process. One example of this is that researchers found that participants had a heightened sense of time after surviving cancer. Finally, Drew (2005) shares narratives of individuals who underwent cancer treatments as children, revealing how they came to terms with being adult cancer survivors.

There has been a recent upsurge of scholarship exploring lived experience of care within the geographic literature. Eggleton, Kearns, and Neuwelt (2017) invite patients to create drawings that explore their experiences of waiting rooms. They note that co-creating insights with participants through interviews help bring to life meanings and also challenge power embedded in sites of health care. Wong and Regan (2009) conducted focus groups with individuals living in rural communities in British Columbia, Canada to examine patient perspectives on access to health care services for rural residents. They find that access depends on individuals’ perception of a need for care, whether they are able to get the care they require in their community, and whether they have the means to attain care or obtain required services in their home community.

Cloutier-Fisher and Joseph (2000) observe service user and provider experiences of care restructuring in Ontario. They discover that service restructuring creates uncertainty in regards to continuity of care. Placing emphasis on people's perspectives and highlighting their experience of care sheds light on new understandings of care, such as vulnerability, from a care recipient perspective (Cloutier-Fisher & Joseph, 2000). Atkinson et al. (2015) note that while illness narratives are increasingly used within the geography literature, positive experience dominates these accounts, with minimal critique of the political climate that surrounds such experiences.

The Voice of the Researcher

The voice of the researcher is also present within the care literature. Some researchers reveal their lived experiences of disability, illness, receiving care or support, or being a care provider. Sometimes researchers use their voices to reveal lived experience of being a researcher. For the purpose of this study, I focus on studies that reveal the researcher's voice in relation to lived experience of care and support.

Many researchers use autoethnography or autobiography when revealing lived experiences of care. Ellis (1995), for instance, uses autoethnography to uncover her relationship with her partner who was dying. Murphy (1987), an anthropologist, shares his personal account of a progressive spinal cord condition that would lead to paralysis, reflecting on care and diagnosis. Murphy reflects on his experience in hospital and his return home, as well as his struggles to return to work. He explains how a physician's diagnosis and prognosis can instill despair or hopelessness in a patient. Greenhalgn (2001) shares her lived experience of chronic pain and her experience of health care. She outlines her care relationship with her physician over an eight-month period where she was misdiagnosed as having fibromyalgia. Throughout her experience she worked to attain better health care during her treatment. Her story reveals the power that care providers have with respect to impacting patient experience by defining disease and diagnosis and by managing care relationships. Some write explicitly about their experiences of illness or disability. Richards (2008) writes about her experience of end stage renal disease using autoethnography.

Others disclose their experience of providing support or care. Mairs (1997) reflects upon her care relationship with her partner. She notes that the care she and her partner have provided each other, including wound care and assistance in the washroom, has not impacted their attraction to one another or their relationship. Kelly (2016) discloses her relationship with a person who uses Direct Funding: perceptions of impairment, illness, and disability shape encounters within the care relationship (Kelly, 2016). Kelly is friends with the individual in her study, but she also provides support for this person at times.

Many of these studies have in common an exploration of the personal changes experienced by the researcher in the context of care relationships. Here again, lived experience is a valued component of the scholarship. Disability studies was formed and advanced in large part through memoirs and narratives.

Taken together, these studies reveal how the health system, and practices and relations within the system, helps to shape experiences of care from the perspective of care providers or receivers. It is important to include stories of those receiving support because narratives can be used to reclaim experiences that have been previously misrepresented as tragic (Mintz, 2007; Perreault, 1995). They also help to shed light on what it means to be a patient in the healthcare system in a neoliberal political landscape.

Barnes (2012) and Wiles (2011) stress that we must highlight the importance of understanding the experience of care recipients. According to Dierckx de Casterle et al. (2011), observing lived experience of patients reveals "what it means to patients and their families to have to go through the experience of ill health and/or treatments."

There is growing interest in lived experiences of care within the literature, however further explorations of care from the perspective of individuals who have been oppressed, marginalized, and inadequately represented in research are needed within geography (Kaley, Hatton & Milligan, 2019; Power & Hall, 2018; Wiles, 2011) and within the feminist ethics of care literatures (Daly, 2013; Dossa, 2005; Hande, 2017; Kelly, 2016; Morris, 1995). Power and Hall (2018) note that there is an increasing need for research seeking to understand care particularly during this period characterized by individualism, austerity, and commodification (Power & Hall, 2018).

Summary

I pull from disability studies, feminist ethics of care scholarship, and geographies of care perspectives in this study. I explore care as embodied, relational, and emotional (Power & Hall, 2018; Wiles 2011), recognizing that care is shaped through encounters, space, objects, people, and circumstances. I approach care critically, considering the long history of oppression disabled people have faced in the context of care. I employ Kelly's (2016) understanding of care as accessible care*.* This understanding of care connects the feminist and disability literatures, recognizing the tensions in defining care. This perspective realizes that various definitions and understandings of care exist (Kelly, 2016). Within this perspective, I recognize the history of oppression in the name of care, using quotation marks to connote that care was missing from these encounters. I use the term 'care' when referring to instances where individuals receive personal care and assistance following surgery. However, I use the term 'support' when referring to support with daily living. This usage is out of consideration for individuals who contest the term 'care' when referring to support services, while also recognizing that there are times when all individuals need care. I take the position that all people should have opportunities for choice and control, in line with Independent Living scholarship.

In line with feminist ethics of care scholarship, the purpose of this study is to understand care and the impact of care from the perspective of care receivers. I emphasize the importance of care encounters, recognizing that care takes place through social relations (Barnes, 2012). I aim to create research that rejects systematic marginalization and medicalization of patients in health care by including the voices of care receivers and disabled people in this study as important sources of knowledge.

The care literature reveals that care is shaped by multiple forces and takes place within a continually shifting neoliberal political landscape. One example of this is that care scholars focus on how care is impacted by changing neoliberal policies and austerity measures. For instance, care is increasingly taking place in the home and people are being discharged from hospital to home more quickly than ever before (Forbes et al., 2008; Tourangeau, Villeneuve, Laporte, & Berta, 2014). Milligan and Power (2010) suggest that as individuals recover or are cared for increasingly in the home, informal care is viewed as part of familial responsibility, shifting the focus of care away from formal caregivers. Research examining what it means to receive care may help shed light on whether policies and practices in place that impact care are sufficient, and whether there are areas for improvement. This study furthers our knowledge of some of the implications of increasing familial responsibilities, with growing numbers of people being sent home earlier from hospital to recover at home. Research in this area is both timely and consequential.

Atkinson et al. (2015) note that with health care reform taking place, there is a need for research that encompasses collective and relational understandings of health and illness experiences. Among those studies that do include lived experience of care there are many that focus on positive experiences of care (Atkinson et al., 2015). I address this gap in the literature by emphasizing the perspective of those having received care and support. This includes positive and negative accounts. Care literature tends to come from the perspective of health care personnel and is often written for individuals who work in the health system (Richards, 2008). The voices of disabled and aging people and individuals with chronic illnesses and disabilities are underrepresented in care literature (Daly, 2013; Dossa, 2005; Hande, 2017; Hansen, Hanes & Driedger, 2018; Kelly, 2016; Morris, 1995; Richards, 2008). This study addresses this gap in knowledge by focusing on the stories of individuals receiving care. I share both my lived experience of care, as well as narratives of participants, shedding light on what it means to receive care in the current landscape of care in Ontario. These stories help contribute to understandings of care from the perspective of individuals receiving care.

Lived experiences, revealing the ways in which care impacts individuals and families, may lead to changes in these policies in order to improve care and health outcomes. In addition to these benefits, individuals healing from surgery or receiving care, and their family members and support providers, might benefit from this knowledge because people may have similar experiences, which might help to prepare them for what to expect post-operatively. Health care personnel, including physicians, nurses, personal support workers, and family care providers, may get a better understanding of the ways in which their actions within care environments, and the culture they contribute to, help or hinder care.

Milligan and Wiles (2010) suggest that within care-ful geographies we must reimagine care with the consideration that individuals are interdependent and care is relational. It is important to note that care is a public and political issue; care does not just impact individuals. Care is something we will all experience at some point of our lives, beginning from infanthood. This reality suggests that research in this area is important not just for those awaiting surgery or working in the health field but for all individuals.

In this chapter I explored care literature relevant to this study. In the first section, I examined the multiple ways in which care is imagined in the care literature, exploring the interdisciplinary nature of this body of literature. I outlined the tensions and similarities among these fields of study, revealing that care is contested and that the ethics of care is a major stream in the care literature. In the second section, I explored the recent upsurge of lived experience within the literature. The use of the voices of care providers and receivers, as well as the voice of the researcher, is growing within the care literature. Finally, I noted what we know about care from the literature reviewed and how I attempt to address some of the gaps in knowledge in the substantive analysis chapters that follow.

METHODOLOGY AND STUDY DESIGN

This chapter is an account of when and how this research began, and how it transformed over time. My original interest was in the experiences of people who had undergone HKR. My interest in such experiences arose after my mother had the first of two hip replacement surgeries in 2007. For my undergraduate degree capstone project[8] (Cameron, 2008), I used ethnographic methods to collect data derived from what happened in the health system following her second surgery. For my master's degree, I took our retrospective accounts as mother and daughter as the basis for a hermeneutic phenomenological study of HKR (Cameron, 2010). I wanted to continue this kind of exploration for my doctoral research because as Canada's population ages, HKR surgeries are on the rise (Canadian Joint Replacement Registry (CJRR), 2019), and people are being sent home from hospital after surgery sooner than they were in the past. Thus, research in this area is timely and consequential.

My study design evolved overtime and as a result of this I have written this chapter chronologically. In terms of methodology, I situate myself within ethnography. I originally designed a qualitative study anchored in open-ended, in-depth interviews with people who had undergone HKR. By collecting stories of direct experience, I wanted to understand how care is shaped and what it means to receive care within the broader health care system. What are patients

---

[8] An undergraduate degree capstone project is a research project and paper completed as part of degree requirements.

embodied experiences of care? How do carers, both paid and unpaid, help shape experiences of care? How do policies and processes, and the government and institutional bodies that govern these, help to shape care? How do health care workers matter as people navigate the health care system? How and where does care take place? Who provides this care, and under what circumstances? How does all of this impact people receiving health care?

As planned, the completed study works analytically with the narratives of seven former HKR patients. Unexpectedly, it evolved to incorporate my own ethnographic accounts collected as a patient within the health system, and my autoethnographic experience as a recipient of care. Two daughters of HKR patients also took part in interviews. Together, our stories reveal care relations surrounding surgical care, an area of literature where there is minimal qualitative research—and almost none from the patient standpoint (CJRR, 2014; Gray, 2000).

Interviews: Talking to Patients

In the winter of 2012, I began interviewing people who had undergone HKR surgery in Ontario. Post-operative care is a common phenomenon that reflects human experience and patient accounts provide knowledge that others might learn from. Cohen, Kahn, & Steeves (2000) and Van Manen (1990) suggest that interviews can help researchers develop a better understanding of experience and the meanings participants ascribe to particular phenomena.

I interviewed a total of nine people. The recruitment criteria I used included that participants must live in the province of Ontario and have undergone or be waiting for HKR surgery. Seven participants had HKR surgery and two family members of HKR participants took part in interviews. HKR participants underwent surgery within the previous five years and range in age from 55 to 85. Two identify as male and five as female. Four had surgery within the Waterloo/Wellington LHIN area, while the remaining three had HKR in Central West, Mississauga Halton, and South West LHINs. Two of these participants had undergone one knee replacement surgery, two had one hip replacement surgery, one had both of her hips replaced, one had the same hip replaced twice due to complications with the initial surgery, and finally, one had both knees and one hip replaced.

Of the HKR participants who chose to answer questions regarding their socio-economic status, all report their income as above $50,000 a year. Two participants chose not to answer this question. One HKR participant had two daughters in university and living at home at the time of surgery, one had her son living at home, while the other participants’ children were no longer living at home; all HKR participants in this study have children.

The final two participants are family members of HKR participants. Upon arrival at interview locations, two participants had a family member present and asked whether this person could stay. While I had not anticipated this situation prior to conducting interviews, I was happy to have had the opportunity to hear stories from family/informal carers. In both cases, the family member in attendance was the daughter of the HKR participant and they contributed to their mothers' dialogue with me.

During interviews with the participants with family members present, their daughters would chime in at times, filling in gaps and uncertainties. At times they answered questions I posed to their mothers or verified details shared by their mothers during interviews. One participant would ask her daughter to verify timelines throughout the interview. She would say, "Was I in the hospital for three or four days?" or "How long did I wait for surgery?"

The conversations between these mothers and daughters, and the additional details they provide, add another dimension to this data; these daughters provide retrospective accounts of care following HKR from the viewpoint of family members. These additional interview participants add depth to the data because they provide experiential insights from a family member's perspective. This is valuable because with increasing numbers of individuals being sent home earlier post-surgically, much of the responsibility of care may be placed on family members. A familial perspective of care, particularly home based care, is scarce in the existing literature (Smith-Carrier, Pham, Akhtar, Seddon, Nowaczynski & Sinha, 2018). It is therefore important to examine this perspective.

I recruited participants using purposive sampling, including snowball sampling and opportunistic sampling. Purposive sampling is when participants are selected as representative of groups. There are a variety of strategies used by researchers in purposive sampling. Snowball sampling is one way researchers use this type of sampling. In this method, participants recruit other participants (Bradshaw & Stratford, 2010). Most of the participants I interviewed were recruited through word of mouth or snowball sampling. One individual contacted me after seeing my recruitment poster on Kijiji (a popular classified website), and another participant emailed me after seeing this poster on the Arthritis Society website.

I knew many of the participants who took part in formal interviews, several of whom were recruited through word of mouth. Making contact with participants through word of mouth or recruiting participants through friends or family is opportunistic. Opportunistic sampling is when the researcher takes advantage of opportunities to recruit participants (Bradshaw & Stratford, 2010).

Some participants are friends of my family and I know them quite well and others I met for the first time at the interview. My relationships with participants varied. I had not previously met three of the participants. I met two participants briefly years prior to the interviews. I have a close relationship with one participant and therefore have developed a deeper understanding of her experiences and perspective. Atkinson (2006) suggests that what is shared during the interview process largely reflects the relationship built between the researcher and participant. Thus, the depth of relationships and what was shared during interviews was quite diverse depending on these connections.

All interviews lasted between 40–120 minutes and took place between myself and participants at pre-determined times. I used semi-structured, open-ended questions during interviews. This approach helped to focus the conversation on care while allowing participants to speak to issues important to them (See Appendix A: Interview Guide). This interview structure also provided me with an opportunity to ask additional questions as they arose. I was able to ask probing questions that would allow me to seek clarification, ask for examples, or seek further details of events.

I conducted, recorded, and transcribed interviews verbatim after attaining both verbal and written consent from each participant. Participants had the option to refuse both recording and note taking during interviews. All participants agreed to having interviews recorded and consented to me taking notes. I attained consent verbally at the beginning of each interview, as well as provided a written contract to participants prior to meeting (see Appendix B: Letter of Information/Consent).

Participants were provided with an interview guide prior to meeting with me in order to give them a chance to review questions ahead of time. During interviews each participant had the option to discuss any or all aspects of their experiences before, during, and following HKR surgery. They had the right not to answer any questions they chose not to answer. This right was explained to participants prior to the interview via email or by phone and was explained again when each participant was asked to sign a consent form.

Introducing Auto/ethnography: Writing Myself In

By spring of 2013, having completed six of nine interviews, I was well on my way to completing data collection. I was immersed in the life of a doctoral student: spending long hours searching for relevant literature, writing at my computer, and transcribing interviews. I had collected a wealth of literature related to my topic.

In April 2013, a familiar pain in my tailbone region got worse. I recognized the pain because I had experienced it 13 years prior. It was like a toothache deep in my tailbone and in the surrounding tissue; it felt inflamed with pressure. The treatment in the year 2000 was surgical removal of a cyst that had developed into an abscess. That surgery took five months to heal enough that I could return to school, and eight months to close completely. As a result, I missed much of my final year of high school.

The pain I was feeling in April 2013 made me quite nervous because of my past experience. I was afraid I would need to take a leave of absence from school and teaching to give myself time to heal. The thought of this absence caused anxiety. I was afraid of falling behind with research and writing and hoped that my prediction was wrong.

My fear became reality when I found out I would need to take a leave of absence from my studies to undergo surgery. My leave was scheduled to begin September 2013 and I was hoping to return four months later at the beginning of the following semester. Little did I know at the time that this delay would last more than two years. As complications arose, my medical leave was extended and I attempted to return to school, only to end up back on medical leave multiple times. I needed additional surgery in order to close the wound and could not travel to school. My wound finally healed 27 months following the initial surgery.

This situation not only altered the ways in which I collected data, but also the study design and focus. Suddenly I was not just a researcher collecting data through interviews with others. I found myself in the thick of care, accessing hospital services and receiving care at home from formal and informal carers. I was on the other side. I had just doubled my entry points to collecting data.

I journaled throughout this experience and began to wonder how I could use this experiential data in my research. I wrote in the evenings, through the day, and following encounters with health professionals. These events meant expanding my methods of data collection to include notes I took as I navigated the health system, and various documents, including my medical files and nursing records. In that sense, study design oriented to interviews, stories and narratives took a necessary and, I would argue, creative turn to the auto/ethnographic. My observations and fieldnotes are ethnographic and my journal and reflections on my experience as a recipient of care is autoethnographic.

The purpose of ethnography is to develop an understanding of events, people, and place surrounding particular phenomena as part of the broader human experience that others are likely to relate to. In this case, the phenomena of pre- and post-operative care is the focus of the research. Ethnography is often viewed as a method you need to learn through practice. Hammersley and Atkinson (1995) suggest that this perception exists because ethnography is very much associated with naturalism rather than positivism; ethnography is used in order to produce descriptions or explanations of particular phenomena or to develop theories through data collection as opposed to testing hypotheses already in existence (Hammersley & Atkinson, 1995). In other words, research emerges naturally and authentically through the researcher observing and recording happenings in place and with people in real circumstances.

Ethnography consists of open-ended questions and often changes course because it is very much influenced by the researcher, participants, and circumstances (Hammersley & Atkinson, 1995). Whatever happens is recorded and becomes part of the data, rather than data being sought to support or refute what is being claimed.

Ellis, Adams, and Bochner (2011) describe autoethnography as “an approach to research and writing that seeks to describe and systematically analyze (*graphy*) personal experience (*auto*) in order to understand cultural experience” (p. 1). Auto/ethnography provides a methodology where I can write about my story. It gives me the opportunity to draw readers in on an emotional level. Ellis, Adams, and Bochner (2011) suggest that autoethnography invites readers in and encourages individuals to think critically about their own experiences. My hope is that my story can lead to positive change within the health system.

A number of researchers have employed autoethnographic methods when studying care. Ellis (1995) incorporates autobiography and narrative in her autoethnographic writings of caring for a dying loved one. Ellis has written extensively about autoethnography and ways of doing autoethnographic research and writing. Much of her work guides my writing.

Greenhalgn (2001) discloses her observations and recordings from a journal she kept during treatment she received over an eight-month period. In this autoethnographic book, she outlines her experiences and records her interactions with her physician, in addition to including recordings of and discussions about her clinical file. She describes her medical file as taking on an active role in the research because she discussed her clinical file and its contents with her physician weekly. She used this file in an attempt to attain better health care and wellness during her treatment.

Autoethnographic methods have proven to be helpful in uncovering knowledge of the social and cultural processes that help to construct waiting for surgery and recovery. Penner (2014) uses autoethnography to outline how returning to volunteer at a homeless shelter where she previously worked aided in her recovery.

Illness narratives provide a way to story personal experience and elicit change. Frank (1993) writes:

> Illness narratives…are a significant means for studying the social construction of illness as a rhetorically bounded, discursively formulated phenomenon. Reflexively and sometimes prescriptively, illness narratives invoke change, based on understanding illness as a moment at which change is especially possible (Frank, 1993, p. 41).

Church (1995) writes herself into her research using critical autobiography. She reflects on her experience of illness and breakdown during her doctoral studies, drawing from her personal narrative.

I used a number of methods to collect data and strengthen my narrative. I journaled, wrote fieldnotes, and reviewed my medical records. I journaled from the time I felt increasing pain through to receiving care in my home in the midst of pursuing graduate studies. I reflected upon my experiences and emotions in my journal.

Journaling allowed me to explore my voice and recount intimate moments with health care workers, family, and friends post-surgically, capturing personal and often private details that can be hard to reach retrospectively. We are often told these details don't belong in research. They aren't viewed as "scientific enough." However, as Donovan and Moss (2017) note, research including such intimacies sheds light on care relations and can help to reclaim patient experience.

The most commonly used method of recording data in ethnography is observation and recorded fieldnotes (Hammersley & Atkinson, 1995). Fieldnotes include thick and rich descriptions of social processes and the context in which these processes are studied (Atkinson & Hammersley, 1995).

Thick descriptions were first described by Ryle in 1949 (Thompson, 2001). In 1973 Geertz applied such descriptions to ethnography (Thompson, 2001). Thick descriptions include in-depth interpretations and details of the social interactions and culture (Ponterotto, 2006; Thompson, 2001). In order to add my personal reflective layer to this study, I share thick and rich descriptions from my personal journal and fieldnotes. My fieldnotes and journal developed in the context of the natural activities of the hospital and care at home as I navigated the health system as a patient. My goal while in hospital and receiving care at home was not to collect data, but rather to receive care.

I took notes while I observed my surroundings as a patient. Sometimes, as patients, we are seen by health professionals in large wards with small, curtained-off cubicles. This means that another patient receives care just a few feet away, with merely a fabric curtain separating the cubicles. We overhear discussions between family members and health care workers in close proximity. We wait in rooms full of other patients and families. This is part of the patient experience.

I formed relationships with other people while receiving care, and many conversations with various individuals made their way into my journal and fieldnotes. I spoke informally with other patients in waiting rooms and with physicians and nurses during appointments. Sorrell and Redmond (1995) describe ethnographic interviews as “friendly conversations…[with a] clear specific research agenda” (p. 1119). Oftentimes these conversations took place between myself and a care provider while my bandage was being changed or between myself and another patient in a waiting room.

Heyl (2001) suggests that ethnographic interviews differ from survey interviews. Ethnographic interviews often take place between an interviewee and interviewer who have developed a relationship over time (Heyl, 2001), which allows for interviewers and interviewees to have had sufficient dialogue to have an understanding of the meanings associated with particular events and places for each person (Heyl, 2001). Ethnographic interviews generally take place during observation or field visits and develop spontaneously (Heyl, 2001).

Such encounters are an important part of my experience as a patient. They are part of how knowledge develops among patients. I investigated care in natural settings as a patient. I maintain confidentiality of individuals by using pseudonyms in place of names of people and places. My purpose in making these changes is to protect the identity of participants, family members, health professionals, and organizations involved in providing care in these particular cases. No personal or identifying information is shared.

My positionality as a patient and researcher is central to this study, as it impacts the information to which I have access, as well as what I am likely to focus on and record. The wealth of data available to me was immeasurable; my position as a patient gave me access to data I would not have otherwise had as a researcher. My position as a patient gave me access to a wealth of knowledge because those providing my care treated me as a patient rather than a researcher. This meant that I had access to authentic encounters with formal paid and informal unpaid care providers, which gave me an understanding of care from the perspective of a patient. Presumably there might be differences among how patients are treated based on a number of factors. Level of education, gender, and knowledge of and ability to navigate the health system may influence this treatment.

What is recorded within fieldnotes depends on the researcher's observations, their social position and circumstances, and their past and present experience. An individual observing care as a medical professional/researcher will likely have different observations than a patient/researcher. My education and research have always been grounded in disability studies. My background informs my current research, as I am in tune with and watching for environments and social processes that might be disabling or enabling. Had my previous learning been in the medical sciences, my observations might have had a different focus.

It is important to note other groups to which I belong that help to shape my social position as a researcher and patient. I am a white cisgender woman married to a cisgender man. I do not have to worry about being treated differently because I belong to these groups. I do not have to worry about being discriminated against based on the colour of my skin (see McIntosh, 1988).

I have access to higher education, which helps to shape my social position as well. My experience as a woman who has chronic pain, and as someone who underwent surgical intervention to minimize this pain, gives me insight into care as an insider. My embodiment also affects my positionality as a researcher, and thus I felt it was important to include my care experience throughout this study.

In addition to fieldnotes, Ottenberg (1990) explains that headnotes are also part of ethnographic writing. Headnotes are impressions, images, and feelings that may not have been recorded in fieldnotes (Ottenberg, 1990). Headnotes are recorded in our memories and make their way into autoethnographic writing.

My health records also became an important source of data. I collected copies of my health records from all organizations involved in my care. Greenhalgn (2001) collected clinical notes kept by her physician and used these as a source of data in her autoethnography. I collected records from the homecare organization arranging my care and the agency providing this care. These records include my health records of nursing visits and emails sent by the team of nurses providing me with care.

There was an organizational process as well as more formal procedure I would need to complete in order to access my patient records. According to the Personal Health Information Protection Act (PHIPA) (2004) individuals should request access to medical records in writing. I first requested these in writing from both the organization arranging my care and the agency providing nursing care in the home. The organization provided a form for me to fill out, whereas no formal procedure was in place for the nursing agency. Instead I used a form available on the Information and Privacy Commissioner of Ontario website meant to request access to health records.

I faced some challenges in terms of accessing the email communication among nurses from the nursing agency. The agency first denied my request, stating that I could not have access to these. Following this I contacted their head office by phone and sent an email, requesting access to these. I received a response stating that they would try to obtain these. After not receiving these within 60 days, I filled out a complaint form also available on the Information and Privacy Commissioner of Ontario website. After filling out this document and submitting this complaint to the Commissioner, I received access to some email communication sent among nurses.

There is a wealth of data within these files, many of which highlight the ways in which care and recovery are constructed by health care providers and their perspective of events that took place while I received care. I read carefully through my health records and made note of my concerns. I asked questions about these records and notes when speaking with paid health care providers and contacted an individual at the nursing agency to ask further questions about these emails. In this way, my file took on an active role within my care and the research (Greenhalgn, 2001).

Evolving Study

In accordance with the Canadian Tri-Council Research Ethics, this study has been reviewed and approved by McMaster University's Research Ethics Board. Given that this study evolved over time, I had two iterations of ethics approval. The first protocol involved outlining potential benefits and risks to participants in this research study. I noted that participants would experience no more than minimal risk. In order to maintain and respect the privacy and confidentiality of participants and care providers, I use pseudonyms throughout this dissertation.

I noted that depending upon the information participants provide, there may be a small risk that others may recognize them. One instance where such recognition could happen is when a participant shares a story that a friend or family member might recognize. In order to minimize this risk, everything possible has been done to protect the identities of participants, and the identities of families, physicians, health care providers, and the hospitals and rehabilitation centres attended. Participants had the option to change their decision to participate at any time and for any reason, up until the submission of my dissertation. All participants chose not to change this decision or rescind the data shared.

Initially I recruited participants specifically from the Waterloo/Wellington area. Unfortunately, I ran into a number of challenges with recruitment. I began recruitment by approaching orthopedic physicians, family physicians, and hospitals in the Waterloo/Wellington area through phone calls, emails, fax, and in person (see Appendix C for sample recruitment script). The script/letter informed physicians and health care personnel of the purpose of the study, outlined participant criteria, and asked that the attached flyers be distributed to potential participants (see Appendix D for recruitment poster). I hoped that physicians would be willing to share my information with their patients either waiting for surgery or recently referred to orthopedic surgeons. I requested that the recruitment poster also be hung in the waiting room of physician offices.

At this stage of the recruitment process, participant criteria stipulated that participants must be currently waiting for HKR. Unfortunately, I did not receive any responses from physicians and only had the opportunity to speak with one receptionist who told me that the physicians were “very busy” and insisted that the recruitment letter be forwarded to the physician via fax. Even after completing this request, I did not receive a response from the physician or receptionist.

Local bylaws restricted me from putting up recruitment signage in the region, so I was restricted to finding other means to recruit participants. I put ads in local newspapers and posted in online classified ads with the subject “seeking participation of individuals waiting for hip or knee replacement.” I approached retirement homes and recreation complexes and some agreed to post my recruitment on bulletin boards. I filled out an application to post my recruitment script on The Arthritis Society website. They agreed to post my recruitment script on their website under Current Patient Studies and Surveys.

These means of recruitment did not generate a lot of interest from individuals waiting for surgery. I was finally contacted by one individual interested in participating, after months of advertising in the volunteer section of Kijiji, a free online classified site. I was frustrated with the process of recruitment at this point; after spending three months attempting to recruit participants, I had been contacted by just one potential participant.

I also planned to recruit participants through word of mouth. Many of my friends and family knew someone personally, or knew someone connected to someone else, who had previously undergone HKR. Unfortunately, these people had already undergone HKR. It proved difficult to recruit people *waiting* for HKR surgery.

After discussing these challenges with my supervisor, it became apparent that I would need to alter participant criteria and expand the geographical region from which participants were recruited. This modification would broaden the prospective participant base and hopefully generate more interest in the study. I expanded the geographic location of participants to include anywhere in Ontario. My hope was that this decision would lead to additional participants.

I put recruitment posters in online classified ads across Ontario in the hopes of generating more interest. This expanded geographic area was beneficial because many of my personal contacts lived in different localities throughout the province, opening the door to a new pool of potential participants.

It continued to prove difficult to recruit individuals awaiting surgery through these ads. Without physicians passing on my information to potential participants, it was difficult to access people waiting for surgery. The research methods and participant criteria would need to change in order to produce data that would meet the objectives of this study.

I expanded my search to include individuals who had already undergone HKR surgery. I began touching base with my friends and family to see whether they might know someone willing to participate. I was able to make appointments with participants rather quickly. All but two of the participants I interviewed were recruited through word of mouth.

Some of these interviews took place prior to my own surgery, and some while I was still receiving nursing care in my home. The interviews prior to my surgery took place in participants' homes or in coffee shops, depending on their preference. In order to continue to collect data, I made a number of adjustments to my data collection strategies. I started using Skype[9] to interview participants when I was not able to travel to meet with participants in person. Two participants opted for interviews to take place over Skype, one in a coffee shop, and the remainder of the participants chose for interviews to take place in their homes.

---

[9] Skype is an online communication system that allows people to connect face-to-face via video chat or teleconferencing.

The design of this study evolved as my circumstances changed. I knew that being an active service user of the system would impact the ways in which I understood the narratives shared by HKR participants, and thus it was important that I share this impact with readers. As I became a patient in the health system and my circumstances altered, I adapted my methodology to accommodate for my changing embodiment. After speaking with my committee and considering the wealth of ethnographic data at my fingertips, I applied to McMaster's Research Ethics Board for the approval of a revised ethics proposal that included autoethnographic methods of data collection. These revisions were approved and I was able to include my ethnographic data.

This approval enabled me to write fieldnotes, journal about my experience, and collect my health records as I navigated the health system as a patient and researcher. As the research transformed and progressed, so did the focus of this study. My voice and narrative became central to this project and my position as a patient gave me access to the workings of the health system. While my initial plan did not include sharing the intimate details of my post-surgical care, or for my voice to be at the forefront, rich valuable data was right at my fingertips and I had to seize this rare opportunity.

I collected data in various ways, and as such, some data is more detailed and in-depth. I interviewed HKR participants retrospectively about post-operative care, whereas I collected in-depth field notes of my care and journaled for over two years following surgery. I wrote about encounters with health care personnel soon after they took place, and often in the midst of these encounters taking place. I wrote candidly about my frustrations and fears, and the daily happenings of my care and life more generally. Therefore, data collected throughout my post-operative recovery is very detailed, whereas the retrospective stories shared by participants are less detailed. My journal includes my emotions at the time of events; my notes provide a more complete picture of the events, people, and place of my care than data from retrospective accounts. While data collected through interviews is valuable in sharing the voices of those impacted by the health system, the auto/ethnographic methods provide additional layers of depth in regards to details of events, people, and place.

Analysis

Analysis began with writing. As I wrote and read through my fieldnotes, my journals, my patient files, and my transcripts of interviews with participants, I noted similar storylines among our narratives. Storylines became evident as I wrote and read through transcripts, many of which point to the organizing of care.

While I wrote, feelings emerged. This process helped to uncover impressions, images, and feelings attached to my experiences, all of which became important pieces of analysis. My position as a patient not only gave me access to data I did not have access to previously but transformed the perspective of this work. This transformation resulted in my voice being central in this writing. Clandinin and Connelly (1994) state that without the researcher's voice, research is merely a repeat and analysis of work done by others

As Church (1995) explains, writing about the self in this way is not done out of self-absorption, but rather used as a means to write about a world that is made up of various social actors. She writes:

> Writing about myself is a way of writing about those others and about the world which we create/inhabit. The process uses my life, the life of one social being, to penetrate the social relations of "consumer participation." Because my subjective experience is part of the world, the story which emerges is not completely private and idiosyncratic. (Church, 1995, p. 5)

Ellis (2004) describes narrative analysis as "thinking with a story" (p. 197). She suggests that there are three ways to analyze narrative: narrative analysis, thematic analysis, and structural analysis (Ellis, 2004). She argues that narratives are themselves analytic because as individuals tell their stories, they use analytic techniques. Themes are drawn out in thematic analysis. In structural analysis narratives, researchers analyze stories in terms of structure. Storylines come out of narrative analysis.

Words such as waiting, pain, and immobility came up quite frequently, in addition to stories related to contested biomedical practice, increasing familial responsibilities for care providers, and encounters and relationships with care providers. I refer to these patterns among our stories as storylines. I share narratives throughout this thesis and then move outward to consider organizational processes and practices that help to shape these experiences. Our narratives reveal storylines about care relations and the ways in which we contest biomedical practice and procedures. Our stories help to reveal social forces, such as place, social networks, health care workers, and organizations that impact care post-operatively. They also reveal the multiple ways in which we managed our care.

Conclusion

In this chapter I have outlined methodology, study design, and the ways in which this study evolved as my circumstances and embodiment changed. In the chapters that follow, I explore these storylines: being patient, encountering care, and making do. Collectively these storylines help us understand care from the perspective of people receiving care. They shed light on the ways in which care is organized and disorganized, the processes involved in post-operative care, and the policies and practices that surround these processes. Our narratives reveal care from the perspective of patients. The quality of service we wait for, and the system that governs how long we wait and for what services, are revealed through our narratives.

Some of our narratives overlap with multiple storylines. Stories of being patient while waiting for care, for instance, sometimes overlap with stories of encountering care. We often “make do” while we wait for care to take place. While these storylines overlap, for the purpose of clarity, narratives are organized using these storylines. I make note of the various interconnections among our stories as these arise.

Within each findings chapter, I discuss how each storyline points to larger systems of organization within healthcare. Some of these places include hospitals, physicians' offices, health care organization headquarters, and the home. Some people involved in care include patients, family members and friends, nurses, occupational and physical therapists, nutritionists, medical receptionists, and physicians. While the roles of each of these people and professionals differ significantly, all contribute to the construction of care and patienthood in different ways. I illustrate these distinctions throughout each chapter with the dialogue among our narratives. I feature participant narratives throughout using italics. My narratives are flagged using bold font.

BEING PATIENT

Neoliberalism has helped to shape the health system (Power & Hall, 2018; DeFalco, 2016; Milligan & Power, 2009; McGregor, 2001) and impacted expectations around how patients are expected to behave (Hall & Wilton, 2017; Lim, 2010). Care arrangements, partially shaped by austerity measures, continue to individualize and commodify care, helping to generate these expectations (Hall & Wilton, 2017; Lim, 2010). There is, for example, the expectation that patients "be patient" as they wait for care to take place.

Being patient refers both to the ways in which we are expected to take on the subject role of patients in the health system, as well as the expectation that we "be patient." A requirement of being a patient is to also be patient (De Leeuw, Donovan, Shafenacker, Kearns, Neuwelt, Merill Squier, …& Anderson, 2018). Waiting is common in health care settings (Fogarty & Cronin, 2008). People spend more time waiting for care than in consultation with health care workers or receiving care (De Leeuw et al., 2018). Our experiences of being patient happen within the context of a complicated broader health care system characterized by limited government intervention and privatization (McGregor, 2001; Navarro, 2007; Kelly, 2016; Sakellarious & Rotarour, 2017; Yakerson, 2019).

The health system assigns patients a passive role in care encounters (Charles, Gafni, & Whelan, 1999) and expects people to receive care within this system which is designed to deliver care on its own timeline. We were expected to be patient as we waited for referrals to specialists, for surgery and treatment, and for care to take place.

Becoming Patient

> **I felt like I had fallen on my tailbone. The deep ache became increasingly more intense as the day went on. I felt sick to my stomach and had a fever. I called a cab and went to a walk-in clinic. I had no idea what was wrong, but knew I needed to see a doctor because of my pain and fever. When it was my turn to see the doctor, I explained that my tailbone hurt but I had not fallen on it. After examining the area they explained that it was an abscess and that I would need surgery. He referred me to a local surgeon and I was prescribed antibiotics. I was told to go to the emergency department if my symptoms worsened.**
>
> **My appointment with the surgeon was the following month. The surgeon poked and prodded, examining the area and explaining that I would need surgery quickly. He exclaimed that the cyst was the biggest he had seen. I had surgery three weeks later. The surgical wound took five months to heal to the point where I could return to school after medical leave and three additional months to close completely.**
>
> **When I first noticed increasing pain in 2013, 13 years later, I went to a local walk-in clinic. Just a short walk from the university, the office was small, with four rows of chairs in single file. The walls were a pale pink with a small white melamine desk at the far-left corner of the room. It was filled with students who looked to be around 20. After filling out a form and giving my health card to the receptionist I sat anxiously in the waiting room. Based on what happened years prior to this, I anticipated that the doctor would prescribe antibiotics and refer me to a specialist. I would likely need surgery. I came to this experience with some understanding of what I might expect in terms of diagnosis and medical treatment because of my prior experience.**

This time, I knew what I might expect in terms of how medical personnel would talk about my body and condition because I had been through a similar experience before. I had learned what language would be used by health care workers and what information I would need to share with physicians. They would ask where the “site” was when referring to the area in which I had pain.

As patients we do not always own the language that we use to describe our experiences or conditions; our language often reflects what is used amongst health care workers. Our narratives are littered with medical terminology we have adopted through experience with health care workers and as patients in the health system.

I had become an expert in recognizing my bodily changes and I was able to use medical language to express this expertise to health care workers. Among health care workers, an expert patient is considered one who has the skills, confidence, and knowledge to take part in managing chronic disease and health (Shaw & Baker, 2004; Department of Health, 2001).

Having had prior experience of this particular condition and navigating the health system, I knew what to expect. Previous experience in the health system is an important influence in terms of seeking and understanding additional health knowledge (Jordan, Buchbinder, & Osborne, 2010). With my prior knowledge, I had diagnosed myself with an infection and as in need of antibiotics and possible surgical excision. My skin crawled at the thought of reliving the poking and prodding I experienced years previously and I was anxious at the thought of time lost away from school and work.

> **When it was my turn to be seen at the walk-in clinic, a nurse came to the hallway between the waiting room and treatment rooms and called my name: “Keri, you can come with me.” As expected, they proceeded to ask me what the “site” looked like**

and whether they would be able to drain an abscess in the area. I knew they meant the "site" of the pain based on my prior encounters with health care workers. At this point I could not see any swelling, so I responded, "No, but it could be deeper under the scar tissue." They explained that we would need to go to the treatment room.

The treatment room was a light blue/grey with grey stains and white marks where the paint had been scraped off, leaving small pock marks along the walls. A stainless steel table dominated the room. No pillows or blankets were in sight. They asked me to "hop up" on the table and wait for the doctor. The table felt like ice against my skin as I pulled myself up and onto it. The hardness of the tabletop added pressure to an already sore spot on my bottom.

The nurse told me to lay on my stomach with the site exposed while waiting for the doctor. I flushed with embarrassment and was uncomfortable with the idea that my first encounter with this physician would be from behind with my bottom exposed, rather than face-to-face. I had expected that the nurse would ask me to get into this position because this had been my experience many times before when seeking health care for pain in this area.

During previous care appointments, I would comply and lay on my stomach with my bottom exposed. The doctor would always talk to me while standing behind me. I attempted to stretch my body in a way that would enable me to see their faces as they spoke. This time, I chose instead to sit up straight on the edge of the table so that my face would be the first point of contact with the physician, regardless of my increasing pain and discomfort.

Time slowed at this point; each minute that passed felt like five. My arms were covered in tiny goosebumps from the cold and my bottom ached from the added pressure as he entered the room 20 minutes later. They smiled crookedly at me, as though to convey empathy, and said, "I might not be able to do anything here today, but let's take a look." This language is typical of my interactions with health professionals. "Let's take a look" implied that either "we" or some other entity would also be taking a look at my bottom. Nurses would ask "How are we feeling?"

The physician explained difficulty with assessing the problem with scar tissue from a previous surgery in the area. I was afraid that they might say this because other physicians have told me this in the past when I experienced pain. The

> **physician prescribed antibiotics, referred me to a general surgeon, and told me to proceed to the hospital if there was no relief or if a fever persisted within the next few days.**

This scenario is an important example of the embodied and relational process of 'becoming patient.' I took on the role of patient through this relational encounter. This experience, and many of the stories that follow, speaks to how patients are expected to interact with people and objects related to medical care (the examining table, in this case).

My story reveals how I contested expectations of myself as a patient. In this case, I chose to wait until the doctor arrived before getting into the position asked of me. I challenged this biomedical authority by sitting upright and having the physician wait to see the "site" until after we had introduced ourselves face-to-face.

Part of being patient is waiting for care to take place. I began waiting for care from the moment that my fear I would need surgery was confirmed.

> **I waited in the emergency department at the hospital on three different occasions in the weeks that followed. During my first visit in the emergency department I had a fever of 38.8 Celsius, on the second persistent increasing pain, and on the third blood and fluid oozed from the area. Each time they prescribed antibiotics and I was sent home. Because my infection was spreading, I was referred to a second specialist and my wait to meet with them was shorter than anticipated. I met the surgeon in July. They explained that I would need surgery as soon as possible, but I would need a CT (Computed Tomography) and MRI (Magnetic Resonance Imaging) scan. These imaging tests would make it possible to see more details inside the body.**

I knew that this meant long wait times for tests and I also knew what to expect upon arrival for these.

> **I'll need to wear an over-starched blue hospital gown with an open back. Those crappy gowns with just two sets of strings to keep it closed at the back. If I'm lucky, they'll give me two robes so that I can wear one like a housecoat and cover my ass.**

This account speaks to the vulnerability experienced by patients as well as the ethics of care. In this case, it meant being uncertain of how exposed I might be in the hospital waiting room. This situation points to the ethics of care because my level of vulnerability was contingent upon how attentive the health provider would be toward this potential susceptibility.

> **After registering and waiting for a few minutes, a nurse called my name and passed me two hospital gowns. I was relieved to have a second gown for extra coverage. After changing into these, I entered the room where other patients waited. The edges of the room were lined with chairs so that we faced each other. I felt exposed wearing just two thin gowns that barely reached my knees. I had been instructed not to wear undergarments with the gowns either, which amplified my uneasiness. I sat and waited in a room full of strangers wearing the same outfit and with the same look of discomfort on their faces. It looked as though we each wore the same size hospital gown. This meant that some patients were more exposed than others.**

This example is important for our understanding of care because it highlights some of the ways in which patients are expected to interact with and behave in hospital space (Hall & Wilton, 2017; Lim, 2010).

I knew from prior experience that I would need to take hours off from working on my research and writing in order to attend appointments for tests. This knowledge points to patient expertise about medical procedures and potential wait times.

> **I felt nervous about what was to come—I knew I would need surgery and had previous experience of this operation. My memory of surgery and aftercare when I was 17 was around pain and waiting. I would wait for a nurse to call so I could shower before getting my bandage changed. I remembered the feeling of a wooden instrument scraping the inside edges of my wound as the nurse packed gauze inside of it. I recall my day revolving around a nursing visit, intense pain, and extreme nausea.**
>
> **My suffering[10] began the moment I realized I would need surgery and I began reliving memories from my previous surgery. I was anxious about missing school and work, pain, having strangers in my home, and waiting for surgery and healing.**

A nurse who spoke to me before I was discharged home from hospital explained that I would need to wait to shower until immediately before a dressing change. If my bandage were to get wet from an outside source, bacteria could grow and cause an infection. I would need to be patient and wait for a phone call from a nurse before showering each day. They would call 30 to 60 minutes before their arrival. I was never certain of what time a nurse would call to announce their arrival. They could arrive anytime between 8:00 a.m. and 6:00

---

[10] Suffering is not strictly the result of illness or pain (Frank, 2001). Suffering can be based on our feelings associated with time off from work, our fear of pain, our association with tests during previous illness, barriers we encounter in the environment, or encounters with carers.

p.m., depending on their schedule, the other patients they needed to see for the day, and the location of these visits. This meant that sometimes I could be waiting for more than eight hours for a phone call each day.

> **Waiting for a nurse to call is just like "waiting for Rogers." It reminds me of the window of time a cable company will instruct people to wait. It's usually anytime between 9:00 a.m. and 5:00 p.m. For that time period, you just have to wait. You remain at your house and wait for a service provider anytime within this window. You put your plans on hold and wait; you say "no" when your friend calls to invite you out for lunch, you cancel your afternoon meeting as 2:00 p.m. passes, and you spend half the day glancing out the window for the utility van to arrive.**

Most days the only thing on my agenda was the visit from a nurse because I was unsure of the time the visit would take place. Some days I waited for a nurse to arrive so I could go out, attend a family gathering, grocery shop, or meet with a friend. Getting out was difficult due to pain. Waiting for nursing care added another barrier to these difficulties, creating disabling circumstances.

Timing is an important part of being patient. Having my bandage changed was painful, particularly in the early days following surgery. My wound was left open to heal from the bottom up, so a nurse would clean the wound with saline and then pack it with gauze. When the gauze was removed, it would sometimes stick to the base of the wound. Removing this gauze would cause pain. The timing of ingesting pain medication, so that it is at its strongest during a dressing change, is critical. A phone call from a nurse also meant that I could take a pain pill to relieve my pain.

I could take pain medication every four hours. Twenty to 30 minutes after taking medication was when my pain was at its dullest. Over the next four hours, this pain would steadily increase until it was at its most intense four hours later. If I were to take a pill at 9:00 a.m. and a nurse called at 11:00 a.m. to say they would arrive between 11:30 a.m. and 12:00 p.m., the pain might be unbearable during a dressing change because the pain medication may have begun losing effect. It would be too early to ingest another dose of medication. Being patient, in this instance, meant waiting to relieve pain when I was unsure of the timing of a dressing change.

Part of being patient is the expectation that our homes become a health care space and coping with the reorganization of place. As care increasingly takes place in the home, the home space is altered to accommodate for changing embodiment. This means increasing the presence and use of health care products and equipment at home. My home became a place where home care services took place.

Four large cardboard boxes, filled with wound care supplies, lined the top of the blanket box in my bedroom. An overstuffed file folder sat on top of these boxes housing my medical information. I used a commode in the washroom because the toilet seat was too low for me to use comfortably or safely, and I used a walker to steady myself as I moved from room to room after surgery.

Supplies and medical devices began to fill my bedroom. The home space becomes a more public space when health care takes place within the home

(Brown & Barnett, 2004). My bedroom became less private as strangers entered to provide care and as artifacts within my home reminded me of my changing embodiment. These shifts altered the feelings I associated with my bedroom. Instead of being a private place to rest, it became a place where my bandage was changed, where I experienced pain, and where strangers would see my body exposed during treatment.

Participants' Experiences of Being Patient

Liz, a 65-year-old participant who identifies as female, explains how having prior knowledge was helpful for her during her second hip replacement in terms of knowing what to expect—or in other words, in terms of patient expertise. She speaks to the value of lived, experiential knowledge:

> *I would like the hospital system to be set up for meetings for people who have had the same procedures so you can talk to them beforehand and learn more about what happened before, during, and after because after my first surgery I would never have chosen to go to a rehab hospital. Had I realized what it was like I would far rather come home. Going to rehab was a waste of an experience. Once you've been to rehab you are not eligible for rehab through homecare so you only have but two weeks while you're at the rehab center. Whereas if you come home to recover you have a month more. Having had no prior knowledge, I thought it made more sense [to go to a rehabilitation hospital]. For the second surgery I opted to come home. The progress is better there. (Liz)*

Liz suggests that it would be helpful to have peer mentorship available to people awaiting surgery. This mentorship could help people prepare for what they might expect post-surgically while they wait.

Frank, a 72-year-old male participant, also speaks to the value of patient expertise. He explains that he did his own research prior to his second surgery so that he would be better prepared for the experience: *"The second hip I did my own research because I didn't want to go through the same experience"* (Frank). Frank sought expertise from both friends who are physicians and friends who have undergone HKR. He read literature online to gain knowledge as well.

Patients seek knowledge from health professionals and other patients in order to gain an understanding of what they might expect with their own experience (Hartzler & Pratt, 2011). They may seek patient expertise regarding coping strategies, physician referral, and what to expect post-surgically. Online health communities, where individuals join chat groups and other forums to discuss their experience, is one way patients share and seek patient expertise (Civan & Pratt, 2007).

Individuals also share expertise in medical waiting rooms (Civan & Pratt, 2007) and seek guidance and knowledge through friend and familial connections (Jordan, Buchbinder, & Osborne, 2010). Family and friends provide crucial support and knowledge of when and where to seek information related to health and help to process and retain knowledge (Jordan, Buchbinder, & Osborne, 2010).

The ways in which patients seek and share information are important to this study because they bring awareness to the ways in which patients have and share knowledge as participants in their care. They draw attention to the importance of lived experience as a source of knowledge. Traditionally, patients have been constructed as dependent in care relationships (Morris, 1997) within an authoritarian biomedical model of care (Thorne, Ternulf, Nyhlin, & Paterson, 2000). Recognizing participants as experts and knowledge sharers helps to contest biomedical constructions of patienthood.

Being patient often means being compliant by adhering to institutional policy or procedures and following the orders of health care personnel. One institutional procedure that participants brought up during interviews is what they describe as "*stairs to nowhere" (Frank, Liz, Katie).* Participants were told by hospital staff that before they could be discharged from hospital following HKR surgery they would be expected to climb this set of stairs. These stairs do not lead to anywhere. They are a set of four or five stairs with railings and on wheels. These are used solely for teaching HKR patients to navigate stairs before they are sent home from hospital.

Lilith, a 67-year-old female participant who had a total hip replacement, states, *"It was stupid. They literally made us hop up a set of stairs that went nowhere. And this was all to get permission to leave the hospital" (Lilith).* Frank says, *"They literally said you can't go home until you make it up these stairs" (Frank).* Katie, a 69-year-old participant who identifies as female, also refers to these steps during her interview: *"She [therapist] would not let me go home until I went down the hallway and went up the steps and down the steps; I couldn't* *come home until I did the steps" (Katie).* Liz exclaimed, *"How fucking stupid do they think we are? Like….give me a fucking break. It was stupid" (Liz).*

Every participant complied with this expectation in order to be discharged from hospital and did not question the task when faced with it. Retrospectively, however, participants express frustration regarding the stairs. Liz explains that while she was able to hop up the stairs in hospital, she could not climb the stairs at home because they were different. Both the pitch and height of the stairs at home were higher than the set at the hospital.

Liz shares a story that reflects her feelings that she must comply with expectations of her as a patient:

> *I remember I used to hide the pills. I'd put them under my tongue until the nurse left and then spit it out and put it in my pocket. I had a collection of them by the time I was discharged. They gave me two every four hours! It was just too much.*

Liz pretended to take pain pills by hiding them in her mouth until the nurse left the room. She would then spit them out and tuck them into the pocket of her shirt. When I asked her why she did this, she explained that she did not want to appear to be a "*problem patient."*

Sometimes being a patient involves uncertainty about what to expect. At times we share frustrations with being provided with minimal information and being expected to trust the opinion of our carers. Frank explains:

> *I have my car repaired and he says, "You know, there's two options" and he is a professional as a mechanic. I say, "What do you suggest?" I looked at it [the choice between a metal-on-metal or metal-on-plastic joint replacement] and said, "Okay, you know I'm*

> *the one in construction. What would you recommend? If you are in my chair sitting down here and I were the surgeon, what would you select?" And he said, "Absolutely metal on metal." He didn't explain the possible complications.*
>
> *When I went back [after having a hip replacement] and he said, "You know you have to have this replaced because of the metal-on-metal and the fluid," I thought, "Oh boy…I wish I would have known that." He said, "You know, you have to remember that we mutually made that decision." If he would have said that there is a possibility of getting fluid and you may have to have it replaced, I wouldn't have done it… [sigh]. (Frank)*

Frank speaks further about why he chose to follow doctors' recommendations:

> *I think being my age and growing up with doctors [in the family]. My father-in-law and mother-in law were both doctors so they know a lot about medicine and were highly respected many years ago. Doctors always wore white shirts. My wife's father always wore a bow tie…even going fishing. Whatever the doctors said many years ago you never questioned. Absolutely whatever they said.*
>
> *I think that some of these older people having hip replacements still respect the doctors but I think the doctors should be providing much more information of the pros and cons. I really don't think they do today. In fact, I know they don't.*

Frank explains that physicians should provide patients with more details regarding options for medical care, including possible complications associated with such treatments. This information would give people the opportunity to make informed decisions about their care and treatment.

Some participants describe the expectations that physicians have of patients; some surgeons require patients to adhere to specific rules before they will agree to treat them. Barb speaks about what she believes were the expectations placed on her and other patients by her surgeon. Barb believes that in order to receive health care from this particular physician, she had to comply with his expectations of her as his patient.

> *Some say he's miserable and mean. If you don't do what he says to do that's when he's a bastard. First of all, he won't operate if you're a smoker. Second, he doesn't like whining. Number three, he wants [patients] to get up and get going. (Barb)*

Liz explains that a close friend of hers has been in need of a knee replacement for years, but that her family physician continually refuses to refer her to an orthopedic surgeon until she loses weight. *"He tells her she has to be under 200 before anyone will operate, and she is just beside herself" (Liz).* Stories such as these point to the various ways in which patients are expected to adhere to particular rules or expectations. Without following orders, some patients may be denied medical treatment.

Both participants and I share stories of this initial period of waiting. Bill, a 55-year-old male participant, spoke at length about his discontentment with the aspect of waiting for an appointment with a specialist after speaking with his family physician about his pain:

> *We went to my doctor and they took X-rays of the hip and the diagnosis was arthritis involving tendons and cartilage. In their medical opinion it was deteriorating. My family doctor told me "parts give out," you know? Just like parts give out in cars. He said "You know, yours is going."*
>
> *I started out still working and doing what I was doing, but from the late summer/fall till March I was still able to work and everything. It kept getting tougher and by the time I finally had my appointment with the orthopedic surgeon, which was booked in November, was a four- to six-month wait for just a 15-minute visit, you know? [sigh] I have two kids in university and need to work for*

> *at least another 8-10 years to pay for it…It just kept getting worse and worse. (Bill)*

Bill explains that his condition continued to deteriorate quickly as he waited for an initial assessment with a surgeon. Sjöling, Ågren, Olofsson, Hellzén, & Asplund (2005) note that individuals awaiting HKR often experience varying degrees of suffering; they experience pain, immobility, and frequently an altered sense of identity. People often feel as though there is no one available to address their concerns while they wait (Sjöling et al., 2005).

Bill's pain level rose and his mobility decreased while he waited. Over time it became more difficult for him to continue working in a warehouse and thereby remain in a position where he would be able to provide financially for his family. Bill looked down at his hands and sighed as he spoke of the period of waiting for an appointment with his surgeon and his need to work for an additional eight to 10 years following surgery in order to continue to provide for his family until retirement.

Bill discontinued working while waiting for a surgical date due to increasing pain and decreasing mobility. He was able to resume working six weeks after surgery, 10 months after his initial visit with his family physician. This time away from work added financial difficulties because Bill is the main income provider for his household. While Bill would be eligible for EI Sickness benefit, the maximum amount he would be eligible to receive was 55% of his income, in addition to the family supplement. Bill's two children were both in university, so he expressed feeling anxious about further stretching funds. *“That's another thing that preyed on my mind because I want to hold on as long as I can doing what I'm doing for you know? I've got kids in university and got to work” (Bill).* Sometimes conditions deteriorate and pain increases while waiting to meet with a surgeon, which can have an effect on finances and quality of life.

Stories that reveal the expectation that we be ‘patient’ patients were common amongst patient narratives. Sometimes this means being patient while waiting for necessities like assistance in the washroom, help with bathing, or getting a warm blanket. These circumstances mean that individuals must rely on informal care from family or friends because they cannot wait for these necessities from formal carers.

Frank expresses dissatisfaction when he speaks about his experiences of waiting and expectations that he be patient while waiting for assistance:

> *I woke up one night and I was freezing… We must've waited a good half hour [after using the call bell] so we both [he and his roommate in hospital] started to yell… finally somebody came in and said, “Like, what's your problem?” And we said, “We are freezing!” And she said, “I’ll bring you blankets.” About 20 minutes later she came in the room with two blankets and she threw them in the chair which we couldn't reach. We couldn't get out of bed as we had had our surgery that day. So we said, “This is ridiculous.” (Frank)*

Frank’s voice trembled and he shook his head as he shared this story with me. He believes that the nurse left the blankets just out of reach to *“teach them a lesson”* about failing to wait patiently as expected. His story reveals power in the relationship between nurses and patients who are expected to be patient while they wait for care.

Frank was also expected to be patient while waiting for his intravenous medication to be refilled while the warning bell on the machine alarmed. Frank felt that he was reprimanded for failing to be patient and increasing his volume by yelling to get their attention:

> *I had the intravenous and the bag was empty and as soon as it was empty it started to beep. I waited and I waited and I pulled my cord and it's beeping and beeping. I thought, "Oh my God!" I pulled the cord another three different times and my neighbour pulls his cord. This thing was just going ballistic. No one was coming in. The intravenous thing was plugged into the wall so I pulled it out. Well there's an alarm on it when you unplug it too and it was even louder. Immediately the nurse came in and did she ever give me shit. … was I ever reprimanded for that. (Frank)*

Bill shares these frustrations with expectations that he be patient:

> *She [nurse] said I'll be back in two minutes and it was a good 30 minutes and nobody came back and there was a cord in the bathroom so I pulled it…nobody came. I got up to walk but I couldn't get back into bed… she said, "you weren't supposed to get up on your own!" and I was like…it was 38, almost 40 minutes, and I pulled the cord twice and my roommate said he even requested somebody come in. I said I'm just tired and I was in pain and wanted to get back. I was reprimanded after waiting 40 minutes. Like reprimanded [laughter]. (Bill)*

Bill felt he was reprimanded for not being a 'patient' patient. Bill was considered at risk of falling because he had just undergone hip replacement surgery. He had been asked not to attempt walking without support from another person. However, after waiting 40 minutes, Bill decided to try to get up on his own.

The expectation that patients be patient is a common thread amongst participant narratives. Marg, a 69-year-old female, shares a story of waiting for assistance in the washroom:

> *When you're sick people don't realize that the patient, when they are sick, and when they ask you for a favour and they ring the buzzer, they need to go to the washroom that means they need help now, and you don't just shove them in a bathroom, you know they need help. Don't shove them in a bathroom and leave. You gotta stay there and help them. She didn't do that. I had to wait a long time. (Marg)*

Marg's narrative points to the expectation that she be patient while waiting for help in the washroom.

Liz described a story of waiting for her sheets to be changed.

> *I remember sitting having someone change a bedpan and they spilled pee all over my sheets. It was two shifts later before they were changed. At that point I was bedridden and couldn't do anything about it… (Liz)*

Liz waited in an unclean bed until a nurse was available to change her sheets. Her story reflects the expectation that she be patient while waiting for care to take place.

Analysis

Our stories draw attention to the ways in which being patient is tied to the organization of health care within and between different welfare state systems. Austerity measures increasingly informalize care by reducing public spending on health care (England, 2010; Hande, 2017; Hochschild, 2003; Milligan & Power, 2010; Power & Hall, 2018) and transferring the responsibility for care from the state to individuals (England, 2010; McGregor, 2001; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002). These trends are evident, for example, in the reduction of paid formal care and support services (Forbes et al., 2008; Yakerson, 2019). Some public and private health care services are subcontracted and take place through public-private partnerships (Hande & Kelly, 2015; Whiteside, 2009; 2011).

The restructuring of health care has led to increased workloads for formal care providers (Zeytinoglu et al., 2015), which puts constraints on what they can and cannot do (Hall & Wilton, 2017) and restricts the time they have to dedicate to providing care for each patient (Bains & Cunningham, 2015; Denton, Zeytinoglu, Davies, & Hunter, 2006; Williams, 2006; Yakerson, 2019; Zeytinoglu et al., 2015). This current institutional model of care is insufficient (Berry & Curry, 2012). Hospitals are overcrowded (Berry & Curry, 2012) and the public health system is underfunded and understaffed (Yakerson, 2019), resulting in poor conditions for nurses because they are overworked (Zeytinoglu, Denton, Plenderleith, & Chowhan, 2015), and for patients because their needs are not being adequately met (Baines & Cunningham, 2015; Berry & Curry, 2012; Forbes et al., 2008).

The waiting period between an initial visit with a family physician to discuss concerns and getting an appointment date with a specialist in Ontario varies based on the physician performing the operation, the hospital in which it takes place, and the type of surgery. According to the Health Quality Ontario (2016), the average wait time for hip replacement surgery in Ontario is 247 days. This varies across the province, however. For example, the average wait time for hip replacement surgery in the Waterloo/Wellington Region in 2016 was 379 days (Health Quality Ontario, 2016), whereas the average wait time in the Peel Region at the same time was 197 days (Ontario Ministry of Health and Long-Term Care, 2016).

Participants and I waited between six weeks and five months from an initial physician referral to a specialist and our first assessment with a surgeon. We waited as our pain increased and/or mobility decreased. Many of us reference long wait times for surgical intervention as a source of aggravation. As I continued to wait for an appointment with a surgeon, my infection and pain worsened.

While the number of individuals undergoing HKR is continuing to rise (Canadian Institute for Health Information, 2017), post-surgical hospital stays have decreased significantly (CJRR, 2019; Stabile, Laporte, & Coyte, 2006) as people are being sent home more quickly after surgery than ever before (Denton et al., 2006; Williams, 2006). The median length of stay in hospital following HKR surgery went from four days in 2013-2014 to just three days one year later (CJJR, 2019). This is down from CJJR (2014) reports of hospital stays changing from five to four days in 2011-2012.

As a result of austerity measures that cut funding for publicly funded formal care, people are sent home increasingly earlier post-operatively and more care is taking place at home (Denton et al. 2006; Williams, 2006). Receiving care at home is both part of being patient as well as one way that care is informalized as the responsibility of care is shifted to individuals.

Home care nurses see various patients each day and travel between patients who each live in different residences and often across wide geographic areas (Fitzpatrick & Neis, 2015), which leaves them with limited time to complete care tasks (Denton, Zeytinoglu, & Davies, 2003; Kushner, Baranek, & Dewar, 2008; Yakerson, 2019). Without the knowledge of how many patients they will see each day, or the needs of these patients, it is difficult for home care nurses to provide patients with an estimated time of arrival. This means that they often have to call to announce an appointment timeline to homecare patients as their day progresses. This situation results in potentially long wait times for patients. Weather conditions, the care needed by each patient, and the time it takes to complete care vary. It is difficult for a nurse to plan their day with these uncertainties and to provide timely care. I spent many hours waiting for a nurse to call to announce their arrival while receiving care at home.

This neoliberal care arrangement helps to shape our experience of being patients as well as forms expectations of how patients are supposed to behave in this system of care (Hall & Wilton, 2017; Lim, 2010). People are expected to be patient while they wait for formal care to take place or are expected to have informal care providers—family and friends—take on the responsibility of providing the support they need (Forbes et al., 2008; Yakerson, 2019). Our stories of being patient reveal the subjective positioning of patients in order to facilitate the running of the system. Constraints created by this system help to shape expectations that patients "be patient" while they wait their turn for care. Cuts to government funding and the movement of responsibility from the state to individuals help to create sentiments around how caregivers and receivers are expected to behave (Hall & Wilton, 2017). The same is true of expectations patients have of nurses. Our narratives reveal that we expected nurses to provide timely care; however, there are not enough paid health care providers working in the formal health care system to fulfill the needs of patients (Yakerson, 2019).

Our stories reveal that patients feel as though they experience reprisal when they do not follow these expectations or when they make requests outside of the norm. Frank describes feeling as though he was reprimanded for making noise in an attempt to get the attention of a nurse on more than one occasion. He believed that the nurse left a blanket out of reach as a punishment for falling outside of his expected role. I experienced reprisal when I was denied access to nursing care for four days after making a complaint about the care I received days before.

Consider, for example, the expectation that patients “be patient” while awaiting care. When I was not aware of the time a nurse would arrive to change my bandage each day, I was unsure of the best time to ingest pain medication before a dressing change. This uncertainty sometimes meant delaying pain relief in anticipation of a phone call 30 minutes prior to their arrival. At times I longed for the moment the phone would ring so I could relieve my pain by taking a pain pill. It sometimes meant spending the day waiting for a nurse to call and missing out on opportunities outside of the home.

Marg and Bill both needed assistance getting to and from the washroom in hospital and were expected to be patient while waiting for help. Liz was expected to be patient while waiting for a nurse to change her bedding. Some stories of being patient in this sense evolved to reveal the various ways in which patients oppose waiting and resist the expectation that they be “compliant” by not fulfilling the role of ‘patient patients.’ Bill walked from the washroom to the chair at his bedside without assistance because he was not comfortable in the washroom; he describes being reprimanded for not complying with expectations that he be patient and wait for the nurse to return.

Waiting to use the washroom, and waiting long periods to get comfortable or for a clean place to rest, creates disabling circumstances for individuals awaiting care. Frank expresses frustration with having a blanket placed just out of reach when he was cold. This situation created disabling circumstances because he was not able to reach the blanket and would have to wait to be warm and comfortable.

Sometimes being patient means asserting oneself and exerting agency in order to regain some control over how and when care happens. Frank made noise in order to get assistance from a nurse when he was cold. Bill got up and walked from the bathroom to a chair in his hospital room, against medical advice, because he was uncomfortable and could not wait any longer. He had waited 40 minutes for a nurse to come back and help him. Bill felt as though he was reprimanded when the nurse finally did come in to assist him because he was not fulfilling the role of “patient” patient expected of him.

When participants asserted themselves and sought support in ways that were unexpected (e.g. Frank making noise to get the attention of a nurse), it often resulted in them being perceived as non-compliant impatient patients. Their assertiveness brings attention to the ways in which patients mobilize to contest biomedical practices and expectations. When Frank yelled to get the attention of nurses while in hospital, he was contesting expectations that he follow unwritten rules that patients wait quietly for assistance.

Part of being patient is using the language of health professionals. People working in the health system would speak this language to us and we had to learn it as patients. Negative pressure wound therapy or vacuum assisted closure (VAC) therapy, and hyperbaric oxygen treatment, are just some of the terms spoken to me while receiving care, for example. When referring to hip replacement surgery, to offer another example, nurses and physicians often refer to arthroplasty. As patients we have to learn this language while we navigate the health system.

Our stories of care reflect this development in knowledge and experience of health care over time. At times we felt we were expected to comply with suppositions placed upon us and others where we resisted and pushed back against the expectations of us as patients. There are limits to this resistance, however, and a price to pay when individuals negotiate care—such as being defined as “non-compliant” or a “problem” patient. Our stories reveal the ways in which we are “patients” (as the system defines us) and are “patient” in terms of the expectation that we be patient as we wait.

Our stories of being patient and interacting with people and objects align well with arguments to consider relational explorations of geographies of care and disability (Hall & Wilton, 2017), recognizing human and non-human assemblages in place and expectations of patients. Our stories highlight the ways in which we interact with people and objects in place, taking on the subject role of patients.

Conclusion

In this chapter, I have examined our stories of being patient within the context of a complex health system. I have explored the ways in which we become patients within the health system and the expectation that we “be patient” while waiting for care to take place.

Our narratives point to the constraints under which health care workers are operating and patients are receiving care. These constraints help to determine when health care workers are available, and how much time they have to dedicate to each patient, factors that help to shape expectations that patients “be patient” while they wait for their turn for care. Waiting is commonplace in health care (Fogarty & Cronin, 2008). There are not enough paid health care providers working in the formal health care system to fulfill the needs of patients because our public health system is underfunded and understaffed (Yakerson, 2019).

Participants experienced care in terms of a system that assigned them a passive role as patients. They were expected to receive care as the system is designed to deliver it. Care arrangements are characterized by individualization and commodification, which help to shape how caregivers and receivers are perceived and sentiments about how patients should and should not behave (Hall & Wilton, 2017). Our narratives reveal these attitudes. We were expected to be patient while waiting for care and we were constructed as non-compliant when we failed to meet these expectations.

Our stories reflect this development in knowledge and experience over time. At times, we felt we were supposed to comply with expectations placed upon us to be compliant and patient patients. At other times, we resisted these expectations and pushed back against the expectations placed upon us as patients. When I questioned the care I received and contacted the nurse manager, I pushed back against the expectation that I be compliant and quiet. There are limits to this resistance, however, and a price to pay when individuals negotiate care, such as being defined as “non-compliant” or a “problem” patient. Our stories reveal the ways in which we are “patients” (as the system defines us) and are “patient” in terms of the expectation that we be patient as we wait.

We receive care within an increasingly neoliberal political landscape rooted in individualism and commodification—a landscape that determines when we will receive care and how much time care providers have to give this care (McGregor, 2001; Power & Hall, 2018). I waited countless hours for nursing care at home and participants describe inadequate and poorly timed care in hospital. In the chapter that follows, I explore the ways in which we negotiated care while navigating the health system.

NEGOTIATING CARE

Multiple forces influence care encounters (Milligan & Wiles, 2010). Care is partly shaped by the broader health system arrangement in place (Hall & Wilton, 2017) and austerity measures that help to form the health system (DeFalco, 2016; McGregor, 2001; Power & Hall, 2018). Care takes place within a complex broader care system constituted by private and public systems, including informal and formal care arrangements, which help to determine the quality and quantity of care individuals receive (Hall & Wilton, 2017; McGregor, 2001).

Our stories highlight the impact of the informalization of care. Cuts to government spending limit access to publicly funded care (Whiteside, 2009) and impact the conditions of paid and unpaid care work (Hall & Wilton, 2017; Yakerson, 2019). Publicly funded care is being increasingly outsourced, restricting what care workers can and cannot do for patients (Baines & Cunningham, 2015; Hall & Wilton, 2017) and placing care providers in precarious working conditions (Yakerson, 2019; Zeytinoglu, Denton, Plenderleith, & Chowhan, 2015). Public services that provide care have been dramatically reduced to the point that public funding for home care in Canada is inadequate and fails to meet the needs of patients (Baines & Cunningham, 2015; Forbes et al., 2008). Carers must work within the limitations of this system.

In this chapter, I draw from my experience and data, and the narratives of participants, to explore the second storyline of negotiating care. Negotiating care refers to the ways in which we navigate, experience, understand, and manage care relationships and encounters that are complicated and partially shaped by this complex system. The relationships forged with those involved in providing care, and the quality of our encounters with carers, are important for people post-operatively (Attree, 2001).

Learning to Negotiate

> **One afternoon I was experiencing intense pain after a dressing change. The sharp corners of the Negative Pressure Wound Therapy (NPWT) port were rubbing the inside edges of my wound. I called the nursing agency providing my wound care at home and left a voicemail asking if someone could change my wound dressing because I was experiencing more pain than usual.**
>
> **Angela, the nurse who applied the bandage earlier that day, called me back 25 minutes later. When I explained the issue and asked if she could change the dressing, she replied, “We might have to stop treatment if you can’t tolerate the VAC [NPWT].” She said that she did not want to “make a habit out of this” but agreed to come to the house to change my bandage “this time.” I felt threatened by her tone; this meant that she would no longer support the use of this treatment if I were to continue to complain about its application.**

NPWT is expensive and each person receiving this treatment within the locality in which I live is allotted use of this device for a total of 60 days. After the first 30 days have passed, two extensions of two weeks each may be granted based on a report submitted by a nurse. These restraints helped to create a relational context of anxiety and tension. I worried about the possibility of losing access to this treatment because it appeared to be aiding in healing.

My service plan noted: “Nurse to assess wound healing. Nurse to report recommendation whether NPWT to continue rental if that [is] the recommendation of the nurse.” Angela would take measurements of my wound every other week and indicate how much healing had taken place. She indicated early on in my treatment that she “would just fudge the numbers if we have to” in order to continue funded treatment. This meant that the continued use of this device was partially at her discretion. She was willing and able to try to extend treatment as long as possible and make the system work for me; she was prepared to push back against the limits of the system in place.

After the 60 days have passed, or if continued treatment is not recommended by the nurse before this time has passed, people must pay out-of-pocket for the use of this device if they choose to continue treatment. This treatment must also be recommended and ordered by their physician in order to continue.

Discontinuing this treatment could mean slowed healing, which could translate into additional time away from school and work. It could result in added out-of-pocket expenses if I were to choose to continue the treatment and pay myself. I was stressed at the thought of losing this treatment because it seemed to be speeding the healing process. Her comment implied that if I were to continue to request additional visits for dressing changes, I could lose access to NPWT. I felt threatened by this insinuation.

> **Angela arrived later than expected to change my bandage that day; it was close to 5:00 pm when she arrived. She explained**

that she had had a long day. She had seen some of her patients for the day, but still had to drive outside of town to visit one patient and had others to see after she redressed my wound.

I explained to Angela that I experience less pain when there is extra gauze in the wound. She responded abruptly, stating that "the pain was likely caused by the use of gauze, rather than its application." Angela proceeded to explain that she wanted to try using foam inside the wound instead of gauze. She pulled out a large rectangular piece of black foam. It was approximately 2" thick, 4" wide, and 8" long. She used scissors to shape it to fit my wound. It was narrowest at the base, gradually getting larger at the edges of my skin. She worked like an artist, carefully sculpting a cone shaped masterpiece that would fit perfectly inside my wound.

I took a picture each time my bandage was changed to check for progress. This time I asked her to take a photo of the wound with the foam inside of it so that I could see the difference between the gauze and foam. In the picture it was clear that the foam filled the wound and was overfilled by about an inch because I could see foam sitting above the edges of the wound in the photograph.

Throughout the day I became progressively uncomfortable. I was afraid to call the nursing agency to report this after our conversation earlier that day because she had suggested that the treatment might be discontinued if I proceeded to have pain. A third visit that day could mean an end to NPWT. Instead of calling the nursing agency to report my increasing pain, I took extra pain medication and minimized movement in an attempt to decrease my discomfort.

Around 10:00 pm that evening my partner gasped loudly. He pointed at me and said, "That really looks like blood." I looked down to see thick red blood moving through the tubing attached to the machine. Usually the colour of the fluid in the tube was a light yellow or pink and was opaque; this device is meant to remove moisture from the wound, but bleeding should not occur.

When I saw the blood I felt panicked. I called the nursing agency right away and left a voicemail indicating that it looked like blood in the tubing. The nurse who was on-call that evening called back quickly and told me to turn off the machine right away. She arrived just under an hour later.

When she arrived, she had a concerned look on her face. She made a comment about it [the fluid in the tubing] not being

> **the right colour and that she wanted to change the bandage because of this. When she began removing tape from the outer bandage, I felt tugging at the base of my wound. She tried to remove the foam, but the tugging sensation worsened and caused pain. The nurse sighed, explaining that the foam had adhered to the base of the wound and that she would need to remove it by pulling it out. She explained that this would be painful because some tissue would be removed with the foam.**
>
> **She pulled the foam out slowly and steadily, sections of my wound bed being ripped away with it. She kept saying, “Oh my god. Oh my god. I’m so sorry” as she pulled the dressing from the wound. She communicated with me throughout the foam removal, telling me what she was doing, apologizing for the pain I was experiencing, and expressing sympathy. I felt supported emotionally. I clenched my pillow as she pulled away the flesh. I was in tears because of the pain and trauma, and the nurse kept apologizing. I wanted to scream.**
>
> **Once the foam was removed she took a picture of the wound bed to show me what it looked like. It looked like an imprint in the shape of the foam where tissue had been removed. Blood seeped from the area where the foam had taken a layer of the wound off. I went to bed exhausted, sore, and frustrated.**

It was clear from the photograph that my wound was now deeper, which could impact the measurements in the nurse’s report and thereby not support the continued use of this treatment. The following day I read literature about the application of foam with this treatment. The user manual for the device noted that “foam must not be packed tightly in the wound” and that the foam should be soaked in saline for 15 to 30 minutes if it is adhering to the wound bed. Other literature revealed that inappropriate dressing application could lead to bleeding and adherence of foam to the wound bed (Martindell, 2012; Mirsaidi, 2010). Patients have died from these adverse events (Mirsaidi, 2010). The vacuum pressure from the NPWT device pulls blood from the wound resulting in potentially severe bleeding.

I called the nursing agency to report the incident the next morning. I wanted to be sure that this problem would not be experienced by anyone else and wanted this concern to be taken into account when reviewing the continuation of NPWT.

> **First, I spoke with the nurse manager, Tabitha. Her response was that the nurse could not have made this error and that I was mistaken. I then called the community organization that had arranged that this agency provide care. Jo, the case manager assigned to my case, responded abruptly. She explained that she was not able to address my complaint. I would need to return to the agency providing my care and speak with them further.**

When a complaint is made regarding services supplied through the community organization or agencies arranged through this organization, the case manager must complete a report at that time. Months later, when I was able to access my patient file, it shows that Jo did not complete a report about the occurrence of this error until five days after I reported the incident and after I spoke with her manager.

> **I was frustrated. I felt as though no one had the time to speak with me and they were not willing to listen to my complaint or address my concerns. When Jo told me that she was not able to address my complaint, I replied: “Who is going to advocate for me? Do I need a lawyer?” The voice on the other ended quieted. I let her go soon after explaining that “I felt the conversation was not going anywhere.”**
>
> **Jo called me a few days after this incident. It was Friday afternoon in late October. I was taking a small bag of garbage to the garage through my laundry room. Resting the phone**

> **between my shoulder and my ear, I moved gingerly, taking tiny steps to avoid friction in the wound.**
>
> **Jo spoke sternly and said "you will no longer have access to nursing services in the home." I was in disbelief. I explained that nobody else in my home could change my bandage because they had not been trained and I would need on-call service because my dressing leaked often. I asked whether I would have access to on-call nursing service over the weekend. "No," Jo replied unsympathetically, "the nurses are uncomfortable in your home." I asked her why and she referred to the complaint I made two days earlier and noted that the nurses and organization providing service were concerned that I was going to sue them.**

Jo writes in my health record: "Client states that she wants to hire a lawyer as she feels she has been done personal damage and nothing is being resolved… Spoke with nursing manager. She has had many interactions with client…she believes they have resolved some of her complaints in the past." I had spoken with Tabitha once previously; however, my records indicate that we had had numerous interactions prior to this encounter.

My file also reads: "…asked client if her issue might be stemming from the idea that the VAC [NPWT] therapy would soon be ended. Client admitted this was part of the problem" (Jo). I remember this conversation clearly. I remember feeling as though she was indicating that I had fabricated the story to increase my chances of accessing NPWT for a longer period. When she asked me this question, I explained that the tissue lost when the foam was removed could impact measurements and therefore potentially mean a discontinuation of NPWT. However, Jo's perspective of our conversation was much different and her record of the event helped to construct me as a “difficult” patient. I was viewed as a potential danger in regards to possible legalities by both organizations.

> **I felt as though I was being punished for making a complaint and was viewed as a ‘difficult’ patient as a result of this. I was unsure of how I would manage without the ability to change my own bandage and without any assistance from a nurse. Anxiety filled my chest and I could barely breathe.**
>
> **My partner entered the room a few minutes later. I turned to him and said, “I can’t do this anymore. I just want to die.” I could not believe the words that spilled from my mouth or the feelings that came with them. I wanted everything to be over in that moment; I felt abandoned and completely hopeless. I lost trust in my health care providers that day, and lost faith in the system in place meant to aid in my healing.**

Upon reviewing my patient file from the organization arranging my care in the home, I read “… the nurse that client has made a complaint about is very competent and conscientious about her practice and has been greatly upset by this situation.” This sentiment helped to further construct me as a “difficult” client by suggesting that I made an unwarranted complaint about a particular nurse.

Emails amongst the nurses involved in my care reveal the perspective of carers following this incident. As I read through these emails and my health records, my heart sank. They helped to construct me as a problem and non-compliant patient. This excerpt is from an email written by a nurse on the team of nurses providing my care. She and I have never met. She writes in an email to her manager and the other nurses on her team that she is not willing to provide me with nursing care:

> “I don’t have the time, nor the patience, to tippy toe around someone that wants what she wants when she wants it...” (Rebecca)

It was clear from this email that not only was I perceived as a difficult patient to manage, but that time and patient expectations of me as a patient were a factor in the decision that they not provide care. Another email written by Tabitha that was sent amongst this group of nurses also refers to the time it took to speak with my partner and myself:

> This is just a rant. I had another 45-minute phone call with the clients HUSBAND because he was unhappy with the way I handled things with Keri! I had the same conversation I had with Keri, I think I even used the same phrases! (Tabitha)

It is challenging emotionally to relive these moments. These memories are as vivid today as when they took place. When I reflect on the initial conversation I had with Angela when I asked her to change my bandage a second time that day, I remember feeling disempowered as a patient and viewed as “difficult” for making this request. As a result, I hesitated to call the nursing agency later in the day when I experienced intense pain with the foam—which ultimately caused damage to my wound. This situation speaks to the ways in which we negotiate care with care providers and compromise (sometimes our health and other times beliefs or needs) in order to have continued care and to meet expectations of ourselves as patients.

I chose not to call the nursing agency when I felt pain from the foam dressing later that same day because I did not want the treatment discontinued on the basis that I could not tolerate it. It was not until I was bleeding that I called them. By this time the damage to my wound had already taken place.

When Jo called to announce that I would no longer have access to nursing care, I was in pain constantly, isolated from work and school, and suddenly without access to the care I needed. In one moment I went from merely coping with these circumstances, to being uncertain of whether I had the ability or support needed to continue in this situation. This impacted my trust in the health system and in care providers more generally:

> **Over the weekend when I was told I would be without access to nursing care my NPWT device started beeping loudly in the evening. The machine displayed a code that indicated that the bandage was not properly sealed and was leaking. I was told early on during treatment that if this were to happen I would need to call to have a nurse seal the bandage or change it if necessary. I attempted to tape the edges of the bandage to stop the leak. Because the bandage was on my backside, it was extremely difficult to do this. I used the mirror on the wall of my bathroom to try to see what I was doing. I was unsuccessful and the device continued to alarm.**
>
> **After attempting to fix the bandage myself I called the nursing agency and left a voicemail, noting that I had tried to stop the device from alarming but the dressing was not sealed and I would need assistance fixing this. After over two hours of waiting for a response, Suzy, one of the nurses on the team of nurses who had been coming to my house prior to this incident, called.**
>
> **Suzy called me and asked whether I had heard from a nurse yet. I explained that Jo told me on Friday that I would not have access to nursing service, but that I did not know what to do because I needed help. Suzy explained that it was her night off and that she was not supposed to be working, but that she would come in to fix my bandage leak. Suzy arrived at my house within 30 minutes of our phone call.**
>
> **She explained that she would fix my bandage on her night off because she did not agree that any nurse should leave a patient without support. When she arrived, she said,**

> **“They can’t just abandon you. You’re a patient and need service. It isn’t right. I’m here because it is my duty as a nurse to provide care.” After speaking with her it was clear that Suzy had come in on her night off against the advisement of her employers and coworkers. She said, “I might get in trouble, but I’m not going to just let you sit here without nursing. You need nursing. This is just ridiculous.”**

Suzy came to my house to provide wound care on her night off and without the permission of her manager. She made me feel valued and cared for by coming in to help me on her night off to provide the care I needed. During the vulnerable time when my care had just been taken away, Suzy was able to make me feel as though she cared about me and was still happy to provide me with care. She explained that she might get into trouble for coming in, but that her duty as a nurse comes first. She defends her actions in an email to the nurse manager. She writes:

> I see there is already an issue from some of the other nurses about me doing this [continuing to provide home care service], but as I’ve said from the beginning I’m willing to help if I can and if I wasn’t I would say so. I know I have some perspective of what’s going on, but I don’t know it all. And if it were any other pt [patient] with limited access to care I would do the same…I promise I’m not trying to make anyone’s job harder. I have the impression that my teammates may not be happy with me regarding this situation, but I know less than ppl assume. I’m just trying to do my job and be a nurse.

After speaking with Tabitha, Angela’s manager, and Jo, my care coordinator, I contacted the regional manager at the nursing agency, who was also Tabitha’s manager, Kate. Kate and I spoke at length and I explained that it was against my rights as a patient to be denied care. She agreed and promised to reinstate my care that day. I would have the same team of nurses providing my care, but Angela and Rebecca would not be part of this group of nurses.

I spent a lot of time searching online for relevant policies and procedures to help me navigate the situation and health system more generally. I found a phone number available for patients and their families to report concerns or complaints. I called The Long-term Care Action Line and explained what had happened. When this number is called, the Ministry of Health and Long-term Care is made aware, as well as the organization to which the complaint is made. I was contacted by the person in charge of managing complaints at the organization arranging my care in the community a few days later to set up a meeting in my home to discuss the issues I was having.

The error that took place was not addressed by either organization through this process. It was through emails sent amongst those involved in my care that I learned that managers were aware the error had taken place. Tabitha writes in an email to her manager:

> I'm afraid that by saying, "Okay, you have done thorough research and based on that new information it does appear that Angela applied the dressing incorrectly … then that gives her ammo for the lawsuit!...I almost want to talk to her, but I'm afraid of saying the wrong thing and making it worse again." (Tabitha)

The initial complaint, and construction of me as a problem patient, continued to affect my encounters with carers. Things changed dramatically after the incident with the foam and after my nursing care was reinstated. As nurses from this team began to re-enter my home, I felt as though they did so cautiously.

One nurse in particular was very quiet during visits after the error took place. She stopped making eye contact with me and answered questions with one-word answers. She would come in and remove my bandage, take measurements of my wound, and re-pack in silence. Prior to this incident, we interacted as she changed my bandage, but this was no longer the case. I felt our care encounters had been affected by the treatment error and her fear that I might plan to sue.

Participants' Experiences of Negotiating Care

Participant stories of being patients also resonate with the storyline of negotiating care. Their narratives point to how they are expected to comply with expectations of how patients should act and how they negotiate care. One example of expectations is the supposition that they use the call bell when they are in need of assistance and then wait for a nurse to arrive. Frank explains that a nurse handed him a white cord with a red button on the end and was instructed to use it if he needed anything. Frank refers to the care he received in hospital as "terrible." He makes reference to two incidents:

> *We must've waited a good half hour [after using the call bell] so we both [he and his roommate in hospital] started to yell… finally somebody came in and said "like, what's your problem?" And we said, "We are freezing!" And she said, "I'll bring you blankets." About 20 minutes later she came in the room with two blankets and she threw them in the chair which we couldn't reach. We couldn't get out of bed as we had had our surgery that day. So, we said, "This is ridiculous." (Frank)*

After using the call bell and waiting half an hour for a nurse to arrive, Frank and his roommate yelled in an effort to get someone's attention to provide care. After they were finally able to get their attention and ask for blankets, the nurse came back 20 minutes later and threw the blankets on a chair out of their reach. This meant that after all of their effort to get care (in this case access to warmth/blankets), they were not able to attain care.

Frank and his roommate wanted to get the attention of a nurse on another occasion because his intravenous machine was alarming when it was empty. This time he and his roommate both used their call bells in an attempt to get the attention of a nurse. When they were not able to get their attention using the call bell, Frank unplugged his intravenous machine in an attempt to quiet it. Rather than the alarm stopping, it grew even louder: *"…the nurse came in and did she ever give me shit … was I ever reprimanded for that." (Frank)*

Frank describes being chastised as a result of making too much noise to get the nurse's attention when he was in need of care during the first encounter. He felt he was viewed as a difficult, impatient patient after the blanket incident. This impacted the way he negotiated care during the second attempt to get the attention of a nurse. This time he attempted to quiet the intravenous machine himself by unplugging the cord. When this action resulted in a louder alarm, he was reprimanded.

Bill describes a similar experience when he attempted to get the attention of a nurse to assist him in the washroom:

> *she [nurse] said I'll be back in two minutes and it was a good 30 minutes and nobody came back and there was a cord in the bathroom so I pulled it…nobody came. I got up to walk but I couldn't get back into bed… she said, "You weren't supposed to get up on your own!" and I was like…it was 38, almost 40 minutes, and I pulled the cord twice and my roommate said he even requested somebody come in. I said I'm just tired and I was in pain and wanted to get back. I was reprimanded after waiting 40 minutes. Like reprimanded [laughter]. (Bill)*

After using the call bell that he was instructed to use when he was finished, he waited almost 40 minutes. When a nurse did not arrive to assist him, he decided to try to move himself. He had been instructed not to do so because he was at risk of falling after surgery.

When the nurse came back into the room and discovered that he had gotten up on his own after they instructed him not to do so, she scolded him. Marg had a similar experience, struggling to get care when she used the washroom in the hospital post-operatively.

> *People don't realize that the patient… when they ask you for a favour and they ring the buzzer and they need to go to the washroom that means they need help now, and you don't just shove them in a bathroom, you know they need help. Don't you shove them in a bathroom and leave. You gotta stay there and help them. She didn't do that. (Marg)*

A nurse helped her get into the washroom and asked her to use the call bell when she was finished and wanted to get back into bed. She used the call bell when she was done, but a nurse did not come to assist her right away. She describes the nurse who assisted her to the washroom, but did not stay to help her while she used the washroom, as "*mean*."

Liz explains how she negotiated care by putting on an act in order to satisfy her care providers.

> *I remember I used to hide the pills. I'd put them under my tongue until the nurse left and then spit it out and put it in my pocket. I had a collection of them by the time I was discharged. They gave me two every four hours! It was just too much (Liz).*

Liz pretended to take the pills the nurses gave her in hospital but hid them under her tongue. When they left the room, she would spit them out and put them in her pocket.

> *I had a collection of them when I left…my mother and sister were both nurses. I know there are expectations…and I knew I didn't want to be on the naughty patient list (Liz).*

Liz altered what she did in order to appease nurses and to avoid being viewed as a "difficult" and non-compliant patient.

Part of being patient is being defined as non-compliant or "difficult" when they do not abide by rules they are expected to follow. Participants asserted themselves and made concessions in an attempt to access care or receive good care when needed—in these ways, they negotiated care. They indicate that they felt that health care providers were often insensitive to their needs, describing care as "*terrible*" (Frank) or providers as "*mean*" (Marg). Participants felt, as did I, that they were reprimanded when negotiating care in ways that were unexpected of them—making noise, not waiting 'patiently', and criticizing care.

Lilith tells a story of feeling hospital staff went "above and beyond."

> *They were just pulling their hair out to find out what the heck was the matter with me…they bent over backwards …that Sarah [nurse] that gave me Gravol on the sixth day, she was like an angel to me. (Lilith)*

Lilith describes having a reaction to the medication at the hospital and physicians and nurses attempting to find the problem for two days while she felt unwell and her health continued to deteriorate. After Sarah administered Gravol, Lilith was finally able to rest and feel better.

Lilith expresses not only gratitude for Sarah relieving her discomfort, but also appreciation of the way in which Sarah interacted with her and checked in on her often. Their care encounters reflected good care. Lilith highlights the level of effort, and time, staff in hospital made to help find the issue that was impacting her health in a negative way. Lilith expresses overall appreciation for, and contentment with, the treatment received throughout her post-operative care, stating that her health provider “bent over backwards,” suggesting she went above and beyond her expectations.

Analysis

Care takes place within an increasingly neoliberal political landscape rooted in individualism and commodification (McGregor, 2001; Power & Hall, 2018). Our stories of negotiating care are reflective of a broader organizational structure that limits the length of time nurses are able to spend with patients and what health care professionals can and cannot do (Hall & Wilton, 2017; Yakerson, 2019).

Health care reforms have led to considerable changes in the health system, including through privatization and limited government intervention (Kelly, 2016; McGregor, 2001; Navarro, 2007; Sakellarious & Rotarour, 2017; Yakerson, 2019). Cuts to funding help to shape care encounters and working conditions by limiting what health care workers can and cannot do for patients (Baines & Cunningham, 2015; Hall & Wilton, 2017) and the time they have available to provide care (Bains & Cunningham, 2015; Denton et al., 2006; Williams, 2006; Yakerson, 2019; Zeytinoglu et al., 2015).

The homecare system is characterized by precarious working conditions (Baines & Cunningham, 2015; Zeytinoglu et al., 2015), which translate into limited access to care for patients (Hall & Wilton, 2017; Whiteside, 2009; Zeytinoglu et al., 2015). The working conditions for nurses are poor. Care providers are increasingly being placed in insecure working conditions (Yakerson, 2019; Zeytinoglu, Denton, Plenderleith, & Chowhan, 2015), with heavier caseloads of patients and circumstances where they have little time to dedicate to each patient (Denton et al., 2006; Williams, 2006; Yakerson, 2019). Health sector reform in Canada has led to nurses being increasingly placed in precarious positions of employment in the community—positions characterized by insecurity and non-standard hours (part-time, casual, or contract), with few full-time positions available (Baines & Cunningham, 2015; Zeytinoglu et al., 2015). Working hours are seldom guaranteed and benefits rarely provided (Baines & Cunningham, 2015; Yakerson, 2019). Agencies often hire self-employed nurses without offering any guarantee of working hours and very little, if any, benefits (Baines & Cunningham, 2015; Yakerson, 2019). In 2020, two-thirds of nurses in Ontario will be working in the community, rather than in institutions (Ontario Home Care Association, 2011) and more than half of these nurses will be working part-time or casual hours (Zeytinoglu et al., 2015).

Restructuring has resulted in increased workloads for health care workers and patients in need of more complex care at home (Denton et al., 2006; Williams, 2006). Nurses are under greater pressures to continue to provide the same level of care even with decreasing resources (O'Brien-Pallas et al., 2006; Tourangeau, Patterson, Saari, Thomson, & Cranley, 2017). While workloads for nurses have increased, the time available for providing care to each client has decreased (Yakerson, 2019).

Home care nurses see various patients each day, sometimes across an expansive geographic area (Fitzpatrick & Neis, 2015). This means travel between patients and locations of work that often change frequently and are transient (Fitzpatrick & Neis, 2015). Time allotted for homecare visits is not always adequate to complete complex care tasks, which results in nurses doing unpaid care work to complete tasks (Denton, Zeytinoglu, & Davies, 2003; Kushner, Baranek, & Dewar, 2008).

Time is a factor in many of our stories of negotiating care. The email written by the nurse I had never met referred to not “having the time” to deal with my complaint. This claim draws attention to the limited time nurses have in their insecure and often hectic work schedules. This nurse may literally have not had the time in her day to address my concerns. When I was met with refutation when making a complaint about nursing care, our encounter was partially shaped by the working conditions. My complaint would have added to managers’ workloads by requiring them to fill out paperwork and spend time addressing my complaints.

My request for my wound to be redressed meant prolonging the work day for this nurse, adding more travel time. It might have meant unpaid overtime, and increased pressure to care quickly so that she could get home for the day. My request for additional care could have put a strain on an already overworked nurse with a full schedule for the day, and little time allotted to listen and to care.

These stories are reflective of funding cuts that limit time to provide care. Health care is underfunded and understaffed, increasing pressure on nurses to meet the needs of many patients on their caseloads (Yakerson, 2019). Our current institutional model of care is not working, and not safe (Berry & Curry, 2012). Overcrowding in hospitals results in unsafe conditions for both nurses, who are overworked, and patients, who are under-cared for (Berry & Curry, 2012). Rates of medical error are high in the healthcare industry (Barker & Nussbaum, 2011; Tourangeau, Cranley, & Jeffs, 2006; Treanor, 2000). Nurses are responsible for providing the majority of direct patient care (Barker & Nussbaum, 2011; Tourangeau, Cranley, & Jeffs, 2006). They work long hours, often change shifts frequently, and perform physically and mentally demanding duties. Fatigue levels are associated with work performance (Barker &

Nussbaum, 2011) and the structures and processes in place related to nursing care are a key determinant of patient mortality (Tourangeau, Cranley, & Jeffs, 2006).

One example that helps to highlight these poor working conditions is the workloads of nurses in the community. The day that I asked my wound be redressed, Angela explained to me at 5:00 p.m. that she still had other patients to see, including one outside of town. She saw her first client at 8:00 a.m. that day, so had already had a long day. This brings attention to the precarious nature of nursing care and the overtaxing conditions in which nurses work within this system of care.

Frank describes some of his encounters in the hospital as *“terrible…it wasn't the health care system. It was just the way they [hospital staff] were treating patients. The healthcare system was superb… the staff are just terrible” (Frank).* However, care takes place within the conditions of the health system. Frank speaks about the nurse giving him “shit” for making a lot of noise when he unplugged his intravenous machine and when he and his roommate yelled to get their attention. This system helps to shape care by limiting the quantity and quality of care nurses can provide.

The nurses in these instances would have many patients to care for in a day. They would likely have been occupied with another patient when the initial call bell was pushed and when the intravenous pump was alarming. Nurses may not be able to answer call bells quickly. They must triage the needs of patients when they are working in hectic working environments within a system that governs what they can and cannot do and the time they are able to spend with each patient. Nurses are under a great deal of stress and pressure in this system. Frank's sentiments reflect this reality when he says *"some [nurses] are too busy" (Frank).* The broader care system impacts what health care workers can and cannot do (Hall & Wilton, 2017), which means that at times nurses are forced to prioritize the care needs of some patients over others.

The system requires that nurses be proficient within a system where efficiency is necessary due to reduced funding and increased workloads. These broader relations create tensions in care encounters because they produce an inflexible environment to give and receive care. They are managing an escalating number of patients and working long hours with little job security. Nurses need to work quickly in order to meet the demands of the job. In this sense, health care workers are forced into situations where they have to make impossible decisions. This might mean triaging the needs of some patients over the needs of others. It could mean not having time to answer a call bell for a patient in need of a blanket.

Front line nurses express feeling overwhelmed with their workload and do not feel that they can adequately meet the needs of patients (Berry & Curry, 2012). Research shows that there is an increased risk of complications and higher death rate among patients with fewer nurses providing care (Berry & Curry, 2012; Ontario Nurses Association (ONA), 2017). The number of health care workers available to provide care and time allotted to care for patients are shaped by the level of funding for health care and institutional procedures. In November 2019, the government announced the restructuring of health care in Alberta in an attempt to reduce government spending and balance the budget. The equivalent of 500 full-time front-line positions at Alberta Health Services are set to be reduced. While the number of positions will be decreased, the number of patients in need of care is increasing as the population ages.

In order to meet the needs of patients with limited time, nurses might be expected to work outside of typical hours. Both formal and informal carers perform unpaid labour. Formal care providers essentially “donate” their service, whereas informal carers provide care to family or friends (Baines, 2004). Suzy came to my home to change my bandage on her night off so that I would have access to the care I needed. She expressed feeling obligated to come in on her night off because my care needs would not be met otherwise. This situation draws attention to the unpaid care work nurses are often under pressure to do (Denton, Zeytinoglu, & Davies, 2003; Kushner, Baranek, & Dewar, 2008). Care encounters also reflected responsibility and responsiveness to patients (Dierckx de Casterle et al., 2011). When a nurse sees the patient in the context of social circumstances, rather than as an autonomous individual, it reflects good care. When health professionals have an awareness of social situations, such as patients’ home and work situations and the impact of these situations for patients, it makes it possible for them to be responsive to their needs (Dierckx de Casterle et al., 2011). My encounters with Suzy reflect good care.

Many formal care providers are also performing double-duty caregiving (Ward-Griffin, Brown, Vandervoort, McNair, Dashnay, 2005; Weingart, Pagovich, Sands, Li, Aronson, Davis, R. B., . . . Phillips, 2005). Double-duty caregiving refers to formal carers who also perform informal/unpaid care outside of work (St-Amant et al., 2014). As many as 40% of nurses over 35 are providing care to an aging parent (Ward-Griffin et al., 2015), many while also caring for children and spouses. This reality has important implications, as this phenomenon has increased levels of fatigue and burnout for nurses (Ward-Griffin, Martin-Matthews, Keefe, Kerr, Brown, & Oudshoorn, 2009; Weingart et al., 2005).

Stories of negotiating care connect well with the first storyline—being patient—because they bring to light some of the ways in which patients and care providers are expected to behave. Institutional arrangements help to produce expectations of how individuals—caregivers and receivers—are supposed to act (Hall & Wilton, 2017; Lim, 2010). Care arrangements, impacted by austerity measures, continue to individualize and commodify care, helping to produce judgements around how individuals in the health system should behave. Hall and Wilton (2017) explain that working conditions help to intensify these judgements. “Sentiments concerning the ‘difficult’ or ‘needy’ client or the ‘lazy’ or ‘insensitive’ worker can be intensified within a context of limited support hours and precarious work” (Hall & Wilton, 2017, pp. 734).

There is a presumed etiquette among patients and nurses. We were assigned passive roles as patients in the way that we were expected to receive care patiently within a system designed to deliver care on its own terms; when we did not act in the way that was expected of us, it was a breach of etiquette in the care encounter and relationship. In Frank’s case, he was stigmatized as a complainer. I was presumed to be a non-compliant and difficult patient.

Some of the sentiments from the emails sent within the team of nurses and management bring attention to the limited time nurses have to provide care or deal with situations that might be outside of their regular daily duties. Tabitha writes about spending 45 minutes on the phone speaking with my partner. She uses caps in her email, emphasizing that she spoke not only to me, but also to him. A nurse I had never met expressed in an email that she did not have “the time” to deal with me as a difficult patient. This email was written after I had made a complaint about nursing care. The processing of a complaint takes time, and nurses have little time to deal with patient complaints because the system is not designed for them.

Many of us felt we needed to comply with expectations placed upon us by health care workers and to follow particular orders or accept certain treatment in order to continue to receive care, or in order to attain another treatment option. These stories point to the multiple ways in which we are constructed as difficult-to-manage patients through health care encounters. They also overlap with discussions around ‘being patient.’ Liz, for instance, learned through her interactions with health care workers that she was expected to act a certain way as a patient in the health system. In her case, she chose to hide pills under her tongue to appear as though she was complying and taking her medication. She would then spit them out and put them in her pocket. Gustafsson et al. (2010) found that participants awaiting surgery are well aware that health care professionals have the power to both give and withhold care.

Our narratives reveal our expectations for timely care. One example is our descriptions of encounters where we felt we had to wait long periods for help or care. Marg refers to a nurse leaving her in the washroom without assistance for 30 minutes. She refers to them as "mean." We conclude that nurses are insensitive to our needs or not particularly caring—at times we imply they neglect their duties to care.

When examining this situation through a more critical lens, one realizes it is likely this nurse did not have the ability to stay in the washroom with her due to the constraints of the system (England, Eakin, Gastaldo, & McKeever, 2007). The market-oriented organization of care impacts the financing and delivery of care. Fewer care workers on duty results in reduced time to care for individual patients—nurses are stretched too thin.

Our care encounters are partly shaped and escalated by care arrangements. These stories of encountering care reflect expectations that patients 'be patient' while they wait for care and are indicative of the busy schedules of nurses in the community and in hospital.

We were most vulnerable to the system’s definition of care and how it is delivered during our first encounters of care, not having had previous experience of care and not knowing what to expect within this system of care. Over time, as participants and I continued to navigate the health system, we gained knowledge and experience and learned to negotiate care in ways that aligned more closely with our own needs. We asserted ourselves, exerted our agency, and at times managed to regain some control over how our care was delivered. We asserted ourselves by resisting expectations placed upon us. For example, we were persistent when trying to get the attention of a nurse when the expectation is that we “be patient” patients while we wait for help. When Frank, with his roommate, yelled to get the attention of a nurse, this is one way that he asserted himself.

Our stories reveal that pushing back as a patient is problematic. Emotions are generated out of fear and anger. When I mentioned contacting a lawyer when speaking with my case manager, I was scared, angry, and frustrated that my complaint was not taken seriously. When I made my initial complaint, there was an organizational response. My mention of a lawyer instantly triggered an organizational reaction. The nurse manager called my care coordinator at the organization arranging my care, who then called their manager. I would need to be “managed” due to the concern that I might take legal action. There are complaints procedures in place. Case managers must complete a report using a standard form. The organizational response was to deny me access to nursing care. I had stepped out of my role as a passive patient and become a potential legal threat. I had breached the etiquette of the care encounter by speaking up and questioning care. As a result, I was stigmatized as a complainer. This experience generated information about another layer of the system. On the care relations side, it included a complaint procedure and the management of complaints. On the relationship side, there was an impact on our encounters. Nurses became more cautious and quiet.

There is no room for advocacy in this system of care, and thus we are expected to be compliant—and part of being compliant is never making demands. Threats and punishment become a way that patients are reminded of the etiquette expected of them. For example, I became afraid to call the nursing agency when I experienced discomfort and pain the day of the treatment error, after the nurse providing treatment threatened to stop the use of negative pressure wound therapy if I were to continue to complain. This placed me in an infantilized position; I felt I would have to do as I was told and stop complaining. Part of the expectation is that we stay within our expected role of being ‘patient’ patients—whether or not we are comfortable.

These encounters are partly shaped by the broader health system. Each bandage change and each care encounter takes place within a larger system of care shaped by neoliberalism. The bandage used might not be the appropriate product or the proper size might not be available. This was the case for me when a nurse had to cut a very large bandage so that it would fit my wound. The time available to complete each bandage change is also shaped by constraints within the health system. For example, the homecare nurses working for the agency providing nursing care in my home are paid per visit, rather than hourly. This means that it is beneficial for nurses to work quickly.

Conclusion

In this chapter, I have explored our narratives of care and the ways we negotiate care within the context of the constraints in which health care workers are operating. Unusual or surprising encounters tend to be the ones that remain at the forefront of our minds, and therefore the ones we are most likely to remember and share. Perhaps part of the reason some encounters are so unexpected is because patients have expectations of the care they will receive and the time in which care will take place.

Larger factors feed into the way health care workers provide care, and what care they can and cannot provide. I reveal that care is partly shaped by the complex broader care system in place, which is characterised by individualism and commodification (Power & Hall, 2018). The health system is moving in the direction of a two-tiered system with public and private services by way of subcontracting and public-private partnerships (Hande & Kelly, 2015; Whiteside, 2009; 2011), which impact the quantity and quality of care provided to care receivers (Bains & Cunningham, 2015; Hall and Wilton, 2017).

Our stories of negotiating care highlight the gravity of our encounters with carers and the importance of encounters with those meant to provide support and care. I highlight the ways in which our care encounters are shaped by the larger institutional constraints of the health system. Care takes place within a system with overlapping private and public systems, and with formal and informal care arrangements that help to determine what care providers can and cannot do.

Health care is underfunded and understaffed (Baines & Cunningham, 2015; Yakerson, 2019). The number of nurses available to provide care and time allotted to care for patients in hospital are shaped by a broader system characterized by funding cuts and informalization. This translates into poor working conditions for nurses and difficulty meeting the needs of patients (Baines & Cunningham, 2015; Forbes et al., 2008).

Care takes place within a system of care, with multiple social actors which help to shape these encounters. This means there are not enough nurses on shift (Yakerson, 2019) and nurses are under increased pressures to complete care work quickly, making for stressful and precarious working conditions and impacting the quality and quantity of patient care.

In our stories of negotiating care, we describe care we consider “over and above” what we expect of care providers. Suzy came to my home to provide care on her night off and Lilith’s nurse spent a great deal of time trying to figure out what was causing her illness. These stories of care illustrate the ways in which nurses perform unpaid labour beyond what they are recognized for. They may feel pressure to provide unpaid care because patients could go without needed care if they do not.

Care arrangements help to produce sentiments regarding how caregivers and receivers should and should not behave (Hall & Wilton, 2017). These attitudes are displayed throughout our narratives. Our narratives shed light on the ways in which care receivers and providers are expected to act—and how care providers and receivers expect each other to act. We were viewed as “difficult”, impatient, and non-compliant patients.

A patient perspective helps to shed light on the impact of the constraints within the health system on patients and families. I explore care and the ways in which we navigate care more generally within the context of the broader health system. Our narratives shed light on the advocacy and determination of patients. My behaviour was not what was expected of a compliant patient; instead my behaviour was reflective of a ‘difficult’ and non-compliant patient. There were times when I felt disenfranchised and as though I had been abandoned by my carers and others involved in my homecare service, and times when I felt empowered to fight for my right to health care or treatment. I learned quickly that patient empowerment and voice are often met with hostility. I learned how much the encounters I had with those around me would matter to my continued care.

Our stories highlight the importance of our encounters with carers. I highlight the ways in which our care encounters are shaped by the larger institutional constraints of the health system.

MENDING FAULT LINES

My engagement with stories of being patient and negotiating care reveals significant "fault lines" in formal care arrangements that have opened up as neoliberalism has penetrated and transformed our political and social landscape. In the past few decades, regardless of political "stripe," governments of Western capitalist nations, including Canada, have shifted responsibility, steadily, from the public to the private domain.

While the number of individuals with complex medical needs has risen due to an aging population, cuts to government spending have reduced the number and range of formal/paid services and supports available in response (Yakerson, 2019; Power & Hall, 2018) and increased the responsibility for care by individuals and families in the home (Power & Hall, 2018; England, 2010; Milligan & Power, 2009; Williams, 2002). These shifts point to the privatization of care.

The shift away from publicly funded care, and the placing of greater responsibility on individuals and families to organize their own care, takes place in two ways: the privatization of care in the form of informal, unpaid care (England, 2010; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002) (family and friends providing care, reorganizing the home, building or modifying) and privatization in the form of market-based solutions (the purchasing of care as a commodity in the form of paying for treatment and supplies out-of-pocket) (Forbes et al., 2008; Yakerson, 2019). With reductions to home care services, individuals, families, friends, and volunteers are filling in the gaps around tasks such as housekeeping and meal preparation, and/or having to purchase private services, support, and devices out-of-pocket (Forbes et al., 2008; Yakerson, 2019).

“Mending fault lines,” my third storyline, demonstrates various ways in which individuals and families are managing the cracks and schisms that austerity has opened up in caring arrangements, services, and relationships. It refers to the provisions that we make—informally and privately—to make care happen: the building, improvising, reorganizing and repurposing that create access to space, place, and life itself. Our stories reveal the actions that individuals and informal carers perform as they mend the growing deficiencies in formal care and compensate for missing public services and supports. They reveal how we become active participants in our post-operative care. In this sense, our stories point to the individualization and commodification of care.

Struggling to Address Gaps in Care

> **I don’t know what I would do without them [my parents]. It’s been ten weeks and they are still here [at my house] doing everything. I’m still spending most of the day in bed. My mom brings me breakfast and lunch so I don’t have to get up. My dad is doing all of the grocery shopping and work outside. He did the gutters this week and he’s 64! I feel so guilty that they have all this extra work to do.**

Prior to surgery I did all of the cooking and most of the day-to-day cleaning around my home. Because pain restricted my mobility post-operatively, I was not able to perform these duties as I had prior to surgery. My partner has limited mobility and has the day-to-day support of an attendant to assist him with tasks of daily living and personal care. At the time I had surgery, he had limited funded formal support available for tasks outside of personal care, so he did not have the assistance to partake in household tasks or cooking.

The support provided through the organization arranging my care in the community post-operatively was restricted entirely to nursing care for changing the bandage over my wound. This meant that we did not have assistance with household tasks like cooking or housekeeping when both my partner and I were not able to do these tasks without support.

I would need to arrange informal and private care myself for tasks outside of wound care through family members and friends. My parents provided informal/unpaid care after both of my surgeries. They stayed in my home full-time and provided care and support for 11 weeks following my first surgery and eight weeks following the second. They cooked meals, cleaned, and helped to keep the house in order. This informal care provided by my parents was vital in creating a space where I felt at home and cared for as I healed. Having family fill in these gaps in care meant I could continue to eat healthy meals and keep the house clean while I healed post-operatively.

In addition to providing support in my home, my family provided assistance in the community. My dad did the household and grocery shopping with my partner on a weekly basis for close to two years. My father, mother-in-law, and aunt transported me to and from medical appointments and picked up prescriptions on my behalf when I was not able to do so myself. While I was in a position where I could arrange this informal care through family members, individuals without adequate social support or a network of family or friends available to assist with these supports would have to pay out-of-pocket for this type of care.

When my parents were no longer able to stay at my house full-time to provide care and support, my partner and I arranged for paid/private support. We paid an individual $20 an hour out-of-pocket for six hours a week. They would do some cooking and cleaning two to three times a week. The cost of this support added up quickly and the hours of support were not adequate in terms of meeting our needs.

While my partner's income made it possible for us to absorb the cost of private support for a few hours a week, financing private care is expensive. In cases where one or more persons in the household are not working or when individuals do not have the finances to fund private support, individuals may go without the care they need in the home.

Arranging care in terms of reorganizing domestic space is another dimension of how we mend fault lines. The main level of my home is level entry, with a ramp leading to the front door. There are two sets of stairs inside; one set of stairs leads to the top level of the home housing three bedrooms and a small loft, and the second set leads to the basement. I was not able to navigate stairs or walk long distances post-operatively for months. As a result, I needed to make some alterations to my home space when I was discharged from hospital to home.

> **It is painful to walk from my bedroom to the kitchen. Every movement causes pain at this point. I'll need to sleep in the family room. At least then I won't be isolated in here [my bedroom located at the other end of the house]. I asked two family members to move one of the beds from a spare bedroom into the family room/kitchen area. This way I can nap, watch TV, read, and visit [with family and friends]. This means that I won't be spending the day in my dimly lit bedroom by myself.**

I was able to manage with the space available in my home post-operatively by moving bedroom furniture from a spare room into my family room. The family room is brightly lit because it has a large bay window and three skylights; it is the sunniest room in the house. It is also next to the kitchen, where people walk through, cook, eat, and visit throughout the day; the kitchen/family room is the centre of my home and a place where we congregate as a family. Having a bed placed here meant that my time would be spent with other people and I could be part of the traffic within the home, rather than being tucked away in a bedroom at the other side of my home. I spent the majority of my time in this space because the less movement I made, the less pain I experienced.

Due to the location of my wound I was not able to sit for months following surgery. Bending at the waist was painful because the wound over my tailbone would open up further. I was advised by a nurse that sitting could damage my wound. This meant that I could not sit at the table for meals with family, sit at my computer desk, or sit while driving or traveling. I used what was available in my home to accommodate my changing embodiment.

> **Today I used an upside-down box at the table to eat. I still can't sit, so my only option is to stand to eat, but the table is so low. I feel out of place with everyone else sitting. I keep expecting that people are waiting for me to say something important because I'm standing up at the dinner table.**

I used boxes and stacks of books to raise my plate at the dining table. I would stand and eat dinner at the table while family and friends sat. Having my plate raised high meant I could eat more comfortably without sitting down because my plate was at a height I was used to. It also meant that I could join my family for meals at the table.

My dad placed a drawer upside down on my desk and put my computer and keyboard on top of it to raise the height of the screen and keyboard. The added height from the drawer allowed for me to stand at my computer desk and use my computer without risking wound damage and pain from sitting. Having access to my computer was an important part of keeping me connected to friends and family, aware of the outside world and news, and in touch with work and school. This access enabled me to mark papers when I returned to work and school and provided an opportunity for me to work on my research and writing.

> **I am so thankful I can finally comfortably use my computer. A simple but amazing solution—Dad put an upside-down drawer on my desk to raise the height of the computer and keyboard. It is just high enough that I can stand at my computer.**

As I returned to school and work and as my wound began to heal I was able to sit for short periods of time. I began searching for a desk that would allow me to sit for short periods and to stand at other times. I found an electric sit/stand desk online that would enable me to move my desk and computer from a sitting to a standing position using the push of button.

This device was a great solution for my changing embodiment, but it was also an expensive solution. The cost of the desk was over $600.00, and I would have to pay for it out-of-pocket. I had just returned after medical leave from work and was a full-time student at the time. I had not been eligible for employment insurance during medical leave because I did not have enough working hours banked to qualify for this benefit. I had the cost of supplementary fees at the university to pay for while I was on medical leave in order to qualify for medical and dental benefits as well. My insurance would not cover any of the cost of my adaptive desk either, so my partner and I paid for it.

Out-of-pocket expenses associated with creating access in the home can be costly, and the responsibility for the cost of these accommodations is often placed on individuals and families. My partner was able to help with the cost of the desk and other financial support while I was on medical leave; however, individuals without family or friends able to assist with these costs might have to go without the equipment or assistance they need, or they may feel pressure to return to work earlier than they should in terms of recovery.

I adapted medical supplies by cutting them to the right size and taping the edges. One of my nurses ordered a highly absorbent dressing that kept wetness from the wound away from the skin, but it was much too large for my wound.

> **This new dressing is huge. It is unnecessarily large. It's like a diaper, it's so large. I don't understand why they can't make them to fit this size of wound. It's not like I'm the only person in the world who's ever had one this size.**

I found this dressing extremely uncomfortable because it was oversized, bulky, and stiff. This type of bandage has absorbent beads inside to soak up excess fluid from wounds. As the beads take in moisture from the wound, they expand. All of the edges of the bandage are sealed to keep the beads inside as they increase in size.

I needed the level of absorbency it provided but wanted to shrink the size of the bandage for comfort. I asked a nurse whether it came in a smaller size and they explained that the size that had been ordered was the smallest available. In order to resize this bandage, I would need to cut it and tape the edges with waterproof tape to keep the beads inside the bandage as they expanded.

> **The tape just peels…sometimes within hours. Now I have beads that look like the insides of a diaper everywhere. When it gets wet it just falls out. It's uncomfortable and messy. All the other products just suck. They aren't absorbent so my skin stays wet and gets itchy.**

The tape would peel within a few days of wear, but sometimes within a matter of hours. Clumps of wet beads would fall out of the bandage, which was uncomfortable and would require an additional bandage change. Repurposing supplies was in part mending fault lines because only particular supplies are available through the publicly funded health system. If we require something smaller, we, as patients working alongside health care workers, adapt supplies to make care work.

Sometimes mending fault lines means purchasing and renting equipment. My second operation was done in an attempt to close the non-healing wound from the first operation. The surgeon removed tissue and used a series of stitches that would dissolve at different rates, suturing tissue from the base of the wound to the top. I was told not to bend or sit because the angle and pressure could cause the stiches to tear and the wound to open up. This meant that I could not use the toilets in my home because I would need to bend too far as the seats were low. I write in my journal: "**I don't understand what to do. I can't sit on the toilet because it could tear my stiches. What do they [health care workers] expect me to do?"**

I contacted my care coordinator at the organization arranging care in the community to ask whether I could have access to a commode that sat high enough for me to use without bending. They agreed to provide funding for this equipment for 30 days. Following this, I would need to rent or purchase the equipment myself. The cost to purchase the commode was equal to renting the equipment for two months, so I chose to buy this equipment after the 30 days had passed.

Despite my efforts to avoid wound damage, the stitches tore and my wound opened up just a few weeks after surgery. The surgeon ordered NPWT to be initiated a second time. The organization arranging my care agreed to fund NPWT for 60 days for a second time because the need for this therapy followed a new/second surgery. Once the 60 days had passed, I would have to pay out-of-pocket to continue this treatment.

> **The sixty days is up but Dr. D wants me to keep using the vac [NPWT]. Greg and I decided that we don't really have an option other than to pay for it out-of-pocket. I wish we had private insurance to help cover the cost. I called the company that provides our insurance through school and they told me to send an estimate. They won't cover it. They say it is "outside of the services they provide because it is covered by OHIP." Obviously it's not! Otherwise OHIP would be covering it!**

Once I had exhausted funding for NPWT through the organization arranging my care in the community, I chose to pay out-of-pocket for the rental of this device and bandage supplies for this equipment. My doctor expressed that they felt continuing this treatment would give me the best chance at healing.

> **The rental of the NPWT machine is $435.00 per week... The cost of the bandage, port, and canister isn't even included in this estimate. The bandage supplies cost between $50-$150 per kit [the dressing size and cost of the dressing kit depends on the size of the wound—the nurse suggested the medium kit around $100.00]. Each canister costs $35.00. The dressing and canister have to be changed no less than every three days. This means that in order to continue this treatment we have to pay anywhere between $690.00 and $1095.00 per week! And this is out-of-pocket. And this is if none of the dressings leak and need to be changed. If they leak and we have to start over that's $50-$150 more. How do people do this?**

I paid for this device out-of-pocket for four weeks. I called the organization arranging my care and asked that we have a meeting to discuss my treatment. My doctor's order noted that they wanted me to continue to use this treatment until the wound had closed. I was anxious at the thought of paying out-of-pocket for another month of treatment.

A nurse from my care team, my case manager and her manager, and a patient relations officer attended the meeting. My surgeon attended via teleconference. We spoke at length about what treatments we tried previously and what options were available. The organization agreed to pay for the device using a contingency fund. Staff would measure my wound every week to make sure progress was being made. They would use these measurements to decide whether or not to continue to fund the treatment outside of the 60 days originally allotted.

I was relieved that they were willing to pay for the treatment ordered by my physician if progress continued to be made, although I felt guilty that I had access to care that other people receiving home care did not.

> **I worked my ass off getting to the bottom of how funding works for NPWT. I asked for a copy of the policy everyone kept talking about. Sure enough, there doesn't seem to be one. The policy they provided me says nothing about a timeline! They [organization arranging my care] agreed to fund NPWT through some "special contingency fund." They presented it to be as though they're doing me a personal favour. So, why me? What happens to everybody else who needs this treatment? They just continue to pay for it themselves or go without it? It is so f-ing expensive. I honestly don't know how anyone could afford to pay for this for any extended length of time.**

I was made aware of this contingency fund through my advocacy efforts. This means that other individuals receiving homecare might not have the same opportunity to access this fund, but instead have to purchase treatment themselves once the 60-day timeline has passed or go without NPWT.

I began seeking alternative treatments to healing because my wound was not getting smaller, even with the use of NPWT. NPWT was discontinued when progress was no longer made. I searched online, I asked all of my care providers, and I spoke with family and friends. My formal carers and I tried putting medical grade honey inside my wound, packing my wound with silver, and even burning the inside of the wound with silver nitrate sticks in an attempt to trick my body into restarting the healing process.

> **The last few weeks have been brutal. We tried honey and it made my skin so sticky and wet. A nurse comes in once a week and burns the inside of my wound with nitrate sticks.**

I even ingested the medical grade honey after this method was suggested by a nurse. These measures were not successful—my wound remained the same size for months.

I found a website about hyperbaric oxygen treatment that said that it is 75% to 90% successful in treating chronic non-healing wounds. The treatment facility was within a few hours of my home. I sent an email explaining my situation with my chronic wound and asked whether someone might be able to help. A physician emailed me back within a couple of hours.

The doctor’s email stated that they might be able to help me. They suggested I contact the receptionist the next day to set up an appointment for assessment. The doctor agreed to see me without the referral from a physician and I went in for an initial appointment a few weeks later. The doctor examined my wound first and took a swab to check for infection. He took photographs of my wound using a camera that could measure heat and therefore find potential underlying infection. A nurse also had me blow into a tube to measure my lung capacity and looked inside my ears. Finally, I went for X-rays to check for potential bone infection.

It was over three months before I was called back with a date to start treatment. I was relieved when they called with my first appointment date. I started treatment in November 2015. I went for treatment five days a week for an hour and 45 minutes. This treatment facility was a two-hour drive from my house. This meant that the drive and time for treatment combined would be around six hours a day. Getting to and from treatment was painful and exhausting because I had to sit to drive. I was still struggling at this point to sit for long periods due to pain.

After I had lived with my wound for 27 months, it healed with just 22 hyperbaric oxygen treatments over the course of one month. These treatments were provided through a private organization that operates solely through charitable donations. I found additional facilities that offer this treatment throughout the province, some of which are funded by OHIP, and others that are privately owned. The facilities funded through OHIP require a referral from a physician. Because this treatment had not been ordered by my physician, I would need to seek treatment elsewhere. To access those organizations that are privately owned, individuals must pay out-of-pocket for the treatment and these facilities are not regulated.

Participants' Experiences of Mending Fault Lines

Participants also mended fault lines in care by arranging informal/unpaid care and by paying for private care. Liz and Lilith each have two daughters who provided care post-operatively. Liz's daughters helped by providing meals and assisting with household tasks. They helped her while she used a commode (a portable toilet) after her hip replacement surgery. She was only able to bear weight on one leg, which made it difficult to balance when lowering herself onto and getting up from the commode. "*The girls [Liz's daughters] helped me use a commode. There was no way a nurse was going to be around to help me with things like that. It was a bandage change and that was it" (Liz).* Support outside of nursing care for bandage changes was not provided through the organization arranging care in the home.

Lilith's daughters also provided informal/unpaid care by preparing meals daily and grocery shopping weekly for Lilith and her partner. Lilith did not receive paid/formal nursing care in the home. A nurse came in once to teach her daughters how to change the bandage over her incision. *"A nurse came and* *showed the girls how to do it. That was it" (Lilith).* Aside from this visit, Lilith did not receive formal nursing care in the home.

Marg explains that she asked a friend to remove her surgical staples because she was not provided this service at home post-operatively.

> *They [organization arranging care] wouldn't send a nurse [to her home to remove the bandage]. They said "make an appointment at the clinic." I could barely walk so I asked my friend. She picked up the remover at the store on the way here. What choice did I have? (Marg)*

Marg notes that her friend watched a video online to prepare for removing her staples.

Lilith received formal physiotherapy for her newly replaced hip at home post-operatively. She was provided with this therapy for a limited number of visits through the organization arranging her care in the community. She explains that she was not provided an adequate number of funded visits through the public health system.

> *I'm retired and when I retired my health benefits for my employer ceased and I could not purchase that to go on, so as a result of the extended health benefit I was only allowed through OHIP seven visits from a physiotherapist and she could tell right away I needed more physiotherapy. (Lilith)*

The physiotherapist providing therapy in Lilith's house indicated that she would require more physiotherapy after the funded treatment had run out. This would mean that she would need to pay out-of-pocket for additional therapy because she no longer had access to private insurance through employment.

Managing the organization of domestic space is an important part of the work individuals do to mend fault lines in formal care arrangements. As care is increasingly taking place in the home, individuals must navigate domestic settings which are not often designed with altered mobility in mind. Stairs can be difficult to navigate with altered embodiment post-operatively. Reorganizing the home space and building around obstacles to remove barriers came up frequently in our discussions. Participants reorganized their homes, as I did, in order to accommodate for altered embodiment.

One way participants made do was by creating space on one level of their home where they could sleep and spend the day because it was too difficult to access bedrooms on other floors of the home; participants modified a room on the main floor of their home to accommodate a bed and avoid the use of stairs:

> *We live in a split-level home so what had been the family room level, which was three steps up from the patio of the backdoor…became my bedroom because it is also on a level where there was a bathroom and room to negotiate … from the bed to the bathroom. So we moved our king-size bed down to the family room and that became, basically for a month, there was another chair people could sit in to visit and so that was how he made that part of our home a hospital space. It was just so much better than being stuck in a bedroom up two flights which first of all it would've been difficult probably to manipulate at that point because I can't walk on that leg because I cannot lean on it at all. But at least… also on the family room level I was in tune with what was going on in the household… instead of being stuck upstairs. (Liz)*

Liz's bedroom is on an upper level of her home and she lives in a multi-split level home; her house has four levels. The top floor houses two bedrooms and a bathroom. The floor below, eight steps down, has the kitchen, living room, and dining room. There is a third level just four steps down from the kitchen with a family room, office, and small bathroom. The basement has a large bedroom, a laundry room, and a crawl space for storage. Liz arranged for family members to move the sofa and chairs out of her family room and move her bed into the room on the main floor. This way she could be on one level of the home and could avoid using stairs post-operatively. This would also mean that she would be part of the happenings in her home, rather than isolated on a different floor of the home.

Stairs were a major barrier for participants. For some individuals, stairs were manageable prior to surgery, but became difficult to navigate, and at times impossible to climb, following surgery. All participants who underwent hip or knee replacement surgery were taught to climb stairs prior to being discharged from hospital to home; however, participants shared that they continued to struggle with stairs when they arrived home. As a result, they rearranged furniture to accommodate for their altered embodiment.

All but two participants live in homes with stairs to enter the residence and stairs between levels inside the home. Four out of five participants live in homes that do not have level entry and have bedrooms on the upper level of their homes, while the remaining participant lives in a bungalow. The other two participants live in apartment buildings with level entry through the main doors and elevators to reach their apartments. As a result, many individuals avoided using the stairs at home post-operatively and instead opted to create a comfortable living and sleeping space on the main floor.

Stairs were also a barrier to getting out of the house and into the community. Participants with stairs talk about having difficulty getting in and out of their homes both prior to and after surgery. The entrance to Lilith's bungalow is not level entry; everyone must enter her home by using the stairs. Lilith notes: *"…the main floor was fine but going out was a challenge. I just stuck to staying indoors" (Lilith).* Participants without level entry to their homes were hesitant to venture outside of the home because of difficulty navigating stairs and altered mobility.

Liz chose to stay on a specific level of her home because it was easiest to modify that entrance in a way that would enable her to get in and out of the house. There are eight steps leading to her front door, while only three at the back of the home in the room where she relocated her bed.

Liz describes her husband, Scott, as "*handy*." Liz's femur was broken during surgery and as a result she was not able to bear weight on this leg for five weeks following surgery. She was taught by a physiotherapist in the hospital how to hop upstairs using the handrails and hopping on her other leg. However, while Liz could navigate stairs this way, she had surgery on her other leg just three months prior. Because of this, she was hesitant to jump on this leg and opted to avoid the stairs.

> *I was just beside myself about using the stairs…they expected me to put all this pressure on my new joint by hopping upstairs. I just*

> *didn't feel comfortable or stable enough to do this. Angela [Liz's daughter] and Scott came up with the idea of a ramp and a wheelchair to get in the house. (Liz)*

Scott built a ramp out of plywood and wood to use at the back of the house. He also rented a wheelchair the day she was discharged home from hospital. These measures made it possible for Liz to get in and out of her home without navigating stairs and added out-of-pocket expenses. The cost of the ramp and wheelchair rental would fall on Liz and her family.

The participants who live in residences with a level entry, and the participant living in a bungalow, talk about ease navigating their homes as their mobility changes. *"I didn't have any issue getting around here. I mean it's all one floor. If the elevator were down I would have had an issue, but that never happened"* (Frank). Lilith, who lives in a bungalow, also describes the layout of her home as unchallenging to navigate.

> *That was my bathroom there. I can sleep in the front room. It became the convalescing room and that bathroom…that room had the walker. That room had the walker and the thing to take a shower, the thing to step in and stuff like that, but generally speaking the layout of the place is very conducive to a disability. (Lilith)*

Sometimes family members also consider accessible housing based on the needs of family members. In response to being asked whether any changes were made to the home following surgery, Barb responds: *"Actually, the year that I had my surgery we moved into this bungalow… [laughs] I don't think they [daughter and son-in-law] just did it for me...[turns and speaks to daughter in a* *quiet voice]" (Barb).* Barb's daughter, Pam, responds, *"It was definitely influential. Split-level or bungalow" (Pam).* Barb lives with her daughter, Pam, and son-in-law, Joe. Pam explains that she and Joe took Barb's mobility into account when choosing a home. They decided to purchase a bungalow so that Barb would not have many stairs to navigate.

Participants also mended fault lines by using non-traditional assistive devices for mobility. Traditional assistive devices are contraptions such as walkers, scooters, wheelchairs, and canes, made for the purpose of aiding an individual with mobility. A non-traditional device, on the other hand, is an object used as a mobility aid that is not intended for this purpose. Shopping carts are a type of non-traditional device that participants describe using. They use these to navigate stores and move about their communities. Liz explains:

> *I've been using shopping carts to get around for years. If I carry a walker it means I don't have anywhere to put anything. A cart serves the same purpose [as a walker]…I just had Scott [Liz's partner] bring me a cart when I got out of the van [at a store]. I'd hold onto the railing coming down the stairs [at home] for dear life and get myself into the car. (Liz)*

Liz used a shopping cart to aid with mobility for over a decade before purchasing a walker to use as a traditional assistive device at home. She made do at home by using the railings and furniture to steady herself. She leaned on the vehicles for balance until getting into the car or van. She used a shopping cart to aid with her mobility once she arrived at a store.

Marg used a shopping cart to aid with mobility as well: “*I like the stores with shopping carts…that way I can get around easily. When they don’t have carts, I don’t bother…I can’t grocery shop with a walker” (Marg).* Marg explains that it can be difficult to manage armfuls of purchases while using a mobility device. Some walkers have small baskets attached, but they lack adequate space for grocery shopping. She opted to use shopping carts instead of a traditional assistive device because a shopping cart provides assistance with mobility as well as a place to put items while shopping.

Participants used railings and furniture around the house to get from one place to the next without a traditional assistive device. Railings helped to keep them steady as they navigated their homes. Lilith explains that she used the handrails and furniture in her home to aid with walking from her bedroom to the kitchen and living room. *“I used that railing [points to wooden railing next to kitchen table] …and I walked to the table [motions to the table where we are sitting]… I guess I got around however I could” (Lilith).* Lilith lives in a bungalow and her bedroom is on the main floor of the home. There is a railing from the bedroom to the kitchen. She could steady herself by using the railing and furniture to get from one room to the next. She did not need to use a walker or other mobility device for movement at home because she was able to utilize objects around the home to steady herself.

Using furniture and railings instead of traditional assistive devices made it possible to move more easily without the use of traditional assistive devices. Katie explains that traditional assistive devices can be difficult to manage:

> *I couldn't manage the stairs with my walker. It was impossible to get down them while carrying it. It's heavy, awkward, just impossible. George [Katie's son], when he took me out, he would carry it for me. When I was on my own I'd just leave it. I'd use the railing and grab onto those bushes in the front.*
> *(Katie)*

Assistive devices can be difficult to manage on stairs due to their weight, shape, and size. Participants opted not to use these, and instead held onto railings, furniture, cars, and even bushes, to aid with mobility.

Some of the ways in which we mend shortfalls in the formal care system include renting or purchasing equipment that aids in mobility or is required for healing but results in out-of-pocket expenses. Some participants went without a much-needed mobility device or multiple pieces of equipment because only one could be provided by the organization arranging their care in the community. If an individual had a walker provided through the organization arranging care, for instance, and also required the use of a wheelchair, the rental and payment of the wheelchair would be the responsibility of the patient. Liz shares her experience of the difficulty of attaining the devices she needed through the organization arranging her care at home:

> *I called [the organization arranging care in the home] from the hospital and asked for a wheelchair so I could get in and out [of the house] that way. We figured Scott could ramp the back steps. When I called they said, "Absolutely not, you already have a walker." They*

> *explained that once you have one piece of equipment in place, they won't give you another…whether or not it's what you need. (Liz)*

Katie shares her experience of going without a much-needed mobility aid when she arrived home from hospital:

> *The first day when I came home I didn't have… you know… the wheel thing. Your thing you go to the washroom with the wheels [commode]. I didn't have the thing that raises the seats. I didn't have that. I had to wear diapers. (Katie)*

Katie did not have a commode to use in the washroom the day she arrived home from hospital. This made it difficult for her to use the washroom independently because her toilet was too low. She explains that a few days after her return home the agency providing her care sent a commode to her home. In the meantime, Katie 'made do' by using diapers.

With long wait lists in Canada, sometimes Canadians mend fault lines in care by seeking advice or treatment out-of-country (Crooks, Kingsbury, Snyder, & Johnston, 2010; Turner, 2007). Seeking medical, surgical and/or dental treatment outside of an individual's home country, termed "medical tourism" within the academic literature (see Connell, 2006; Fetscherin, & Stephano, 2016; Hanefeld, Horsfall, Lundt & Smith. 2013), is growing amongst Canadians (Barua & Ren, 2015). Barua and Ren (2015) note that over 52,000 Canadians sought medical treatment outside of Canada in 2014. Increasing numbers of Canadians are choosing to go abroad and purchase surgical services due to perceived long wait times in Canada (Snyder, Crooks, Johnston, & Kingsbury, 2011).

During one of my conversations with Frank, he describes difficulty with decreasing mobility and increasing pain while waiting for a second opinion from another Canadian surgeon following his first hip replacement surgery. Frank was experiencing severe swelling and pain. His mobility was also decreasing as a result. *"My doctor said it was important I get that hip replaced because he is absolutely sure it was the metal on metal [the type of joint replacement that was used] that was causing the collection of fluid" (Frank)*.

The surgeon who performed the initial operation suggested that Frank would need the joint replaced a second time with a different type of joint because of these complications. Frank's pain continued to increase as he waited for a second opinion and the swelling in his leg continued to intensify. As a result, Frank purchased care outside of the public health system in the United States when he was not content with the care provided through the public health system.

Some Canadians choose to pay out-of-pocket for surgical intervention to avoid long wait lists when awaiting a surgical appointment. This situation points to the commodification of care. Care as a commodity creates an imbalance in access to care amongst Canadians. While some individuals may have the financial means to afford paying out-of-pocket, other Canadians must use the public system, and this might mean waiting longer than those who choose to go abroad.

Dr. F explained to Frank that the damage caused by these joints can be permanent and suggested that the surgery be done quickly to avoid further deterioration:

> *…you've got two choices, he [the doctor] said. I can phone a friend of mine up. We worked together at the hospital. He's not going to cost you a penny because I know your medical system. I've worked in trial in [Ontario city] he said. Or, he said, he can do it down here [US] tomorrow or the next day. He said, "I know, you can stay in hotel rooms." I said, "I'm all by myself down here," and he said, "It doesn't matter. We will take care of you. We will put you in a facility." He looked out the window and said, "We will take care of you for a week." I just had to factor it out and before I even asked he said it would be between $120,000 and $130,000. (Frank)*

The out-of-pocket expenses for surgery in the United States would be costly. Because Dr. F had a colleague in a nearby Ontario city willing to perform the operation in a timely manner, Frank chose to return to Canada for surgery. This meant that the cost of surgery would be covered by OHIP and it could happen quickly. Frank had the surgery performed within three weeks of returning home. Frank was able to have surgery in Canada in a timely manner after paying out-of-pocket for an assessment from a physician out-of-country.

Bill also discussed the option of going abroad for surgery:

> *my cousin's daughter-in-law, she is an American and she said that her sister was in orthopedic medicine... she can't believe it took that long [in Canada]. In the states you'd be seen by an orthopedic surgeon within a week, that's the two-tiered health care system, of course we can. You know up here you have to wait and so that's a barrier… If I had a spare 50 grand kicking around absolutely…it would be like going to a spa, you know, doing that, but you pay through the nose to do it, but that's a barrier up here. (Bill)*

Analysis

Mending fault lines is tied to the organization of health care within and between different welfare state systems, and the increasing privatization and commodification of care. My exploration of these narratives reveals both forms of private care (informal, unpaid care and market-based solutions) and exemplifies limited access to publicly funded care provision. We were able to stretch these services through advocacy efforts.

One core aspect of neoliberalism is making invisible vast bodies of people and their work. Invisible care work is largely performed by informal/unpaid care workers (such as family and friends) (Baines, 2004). Our stories bring to light this essential invisible labour. This labour is performed by family and friends in various ways. One example is the work performed by my parents and participants' children. Our families' and friends' care work includes preparing meals, grocery shopping, running errands, cleaning and organizing around the house, creating more accessible areas to navigate, and providing assistance with bathing and eating. In some cases, informal carers even perform bandage changes or remove surgical staples. My parents stayed at my house for months after each of my surgeries to fill in gaps in my care; they grocery shopped, cooked, and helped to keep my home clean.

People are in need of help with cooking, cleaning, and shopping post-operatively because formal care is inadequate. People need multiple mobility devices and medical supplies of various shapes and sizes. However, these needs are not considered essential in terms of formal care provisions or there are limitations put in place in terms of how many assistive devices patients can access or how long the rental of equipment will be provided. The Waterloo/Wellington LHIN funds the use of equipment ordered by an occupational therapist for 30 days (Waterloo/Wellington Community Care Access Center, 2011). Once this time has passed, individuals pay out-of-pocket or through insurance co-payments for the rental or purchase of the device. Thus, public funding is not adequate in terms of meeting patient needs and as a result individuals and families must spend money out-of-pocket to mend fault lines in the system.

One example that illustrates this problem, along with the two layers of my analysis, is from the storyline of mending fault lines. When it came to the need for a commode or other assistive device in the home, participants and I had difficulty getting access to these. The need for a commode was an individual problem for myself because I had pain and difficulty using a standard toilet. The broader social organization of care created barriers in terms of accessing assistive devices because there are limitations put in place regarding their use and medical supplies in the home.

Katie was left with no choice but to use diapers because she was not able to use a standard toilet after surgery and a commode was not ordered by the organization arranging her care in time to have it available the day she arrived home post-operatively. When Liz asked the organization arranging her care that she have access to a wheelchair, she was told that she could not because she had already been provided with a walker through the public system; she could only have one funded assistive device in the home. This left Liz in the position where she would have to pay out-of-pocket for the use of a wheelchair, or go without the mobility device she needed.

Homecare services in Canada are a mix of publicly funded and privately purchased care (Guerriere et al., 2008). Home care is outside of the scope of universally insured services in Canada because it is considered an extended health service (Yakerson, 2019). Individuals purchase care through private channels because our public health system is not dependable or efficient (Yakerson, 2019).

Our stories shed light on the ways in which individuals manage the increasing individualization and commodification of care. With the number of individuals with complex medical needs increasing as the population continues to age, reduced government funding for care has led to fewer formal supports and services related to daily living being provided in the home (Forbes et al., 2008; Yakerson, 2019). As the onus of care is increasingly shifted to individuals at home, people must be resourceful in order to mend deficiencies in care and create opportunities for access with changing embodiment.

For example, supports such as assistance with housekeeping and meal preparation in the home are often not provided through formal care arrangements

(Forbes et al., 2008; Yakerson, 2019). People seeking care are forced into situations where they must take on the responsibility of organizing their care themselves through family and friends or must purchase care privately (England, 2010; Hande & Kelly, 2015; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002; Yakerson, 2019). Some Canadians pay out-of-pocket for surgical intervention in order to avoid long wait lists, which points to the commodification of care. Care as a commodity creates an imbalance in access to care amongst Canadians. While some individuals may have the financial means to afford paying out-of-pocket, other Canadians must use the public system, and this might mean waiting longer than those who go abroad or access care through private health care clinics in Canada.

Our stories highlight the impact of the informalization of care. Informal carers play an important part in supporting health, independence, and quality of life (Peckham, Williams, & Neysmith, 2014). As care is increasingly taking place in the home, family takes on much of the responsibility for care. Informal carers assist us with needs that were not fulfilled by formal carers. They provide care by cooking, cleaning, shopping, and transporting us to and from medical appointments and activities in the community when this support is not provided through homecare services. My dad did the grocery shopping and my mom cooked meals for us. Liz's and Lilith's daughters cooked meals and helped keep their homes clean. Informal care is an important dimension of mending fault lines.

Research suggests that the number of hours performed by informal carers is on the rise. In 2013–2014 the average amount of informal care performed rose from 18.8 hours in 2009–2010 to 21.9 hours (Health Quality Ontario, 2015). This suggests that responsibility for care and support are increasingly being placed on individuals and families and research in this area is of value because the need for informal care is growing.

Grant and Church (2015) note that funding for formal/paid care has been so strict at times that caregivers are forced to provide wound dressing changes—a medical duty that a nurse would be formally trained to complete. A nurse can teach a family member or unregulated care professional how to change a bandage so that the family member can provide this care (Tourangeau et al., 2014). Once care has been delegated to another person, a paid nurse does not need to provide this care. Delegation of care to family members saves the health system money because a nurse no longer needs to go into the home to perform dressing changes (Tourangeau et al., 2014).

A nurse taught Lilith’s daughters how to change her dressings over her incision in just one visit. When I asked Lilith about the kinds of services and supports she had in the home, she replied, *“She [a nurse] showed my children how to change my dressing, so I didn’t need a nurse” (Lilith).* This meant that Lilith had minimal formal nursing care in the home post-operatively. Her family was expected to provide the nursing care that she needed post-operatively informally and unpaid at home. Marg asked a friend to remove her staples because she had difficulty getting to a clinic to have them removed and this service was not provided in the home.

Care can be purchased and the responsibility of healing becomes the job of individuals. In this way people are drawn in as ‘consumers’ of increasingly privatized care. One of the major out-of-pocket expenses for individuals with osteoarthritis include visits to alternative care professionals such as physiotherapists and chiropractors (Li, 2009; Sharif et al., 2015). Lilith purchased physiotherapy privately once publicly funded support for it had run out.

Assistive devices and medical equipment, private caregivers, and prescriptions are out-of-pocket expenses associated with care at home post-operatively (Sharif et al., 2015). One example from our narratives that helps to amplify this point are policies that assert that only one assistive device be provided through the public health system at a time, and for a specified length of time, which mean that individuals and families must take on extra work of locating and arranging for the rental or purchase of equipment—and take on the financial burden of this arrangement.

Liz and her partner paid out-of-pocket for the rental of a wheelchair when the organization arranging her care refused to fund the rental of this equipment because another assistive device had already been provided. I purchased a commode once the publicly funded rental of this equipment had come to an end because I still needed to use it. Katie purchased and used diapers when she arrived home from hospital and did not yet have a commode available to use at home.

My partner and I paid for the rental of a NPWT device as well and purchased dressings and canisters for four weeks because my physician had prescribed this treatment and it could no longer be funded through OHIP. Austerity measures that limit access to assistive devices and medical equipment create barriers in accessing care because individuals need to pay out-of-pocket or co-pay insurance. When devices are provided, there is sometimes a delay in terms of when it is available in the home upon discharge from hospital.

A health system made up of public, private, and informal arrangements also means that, if you can afford to, you can get out of the public system by hiring someone else privately. Frank paid to go to the United States for a second opinion and avoid the wait list in Canada. I purchased the use of a NPWT privately when it was no longer provided through the public health system because I had exhausted public funding for this medical device. My private insurance through school denied my application for funding for this device, so I would have no choice but to purchase it myself when my doctor recommended that this treatment be extended. I also purchased a commode after the period in which public funds were available to provide it. After 30 days, I had the choice to purchase the equipment or rent the device myself. Our individual stories shed light on problems that other individuals might face within the health system.

These limitations apply to everyone; however, the commodification and informalization of care pose challenges because not all Canadians have the financial means to purchase care privately. While some individuals have a social and/or familial network that enables them to fulfill care needs through informal care arrangements, other individuals must purchase private care in the home and community. The majority of homecare services (75%) are related to private payments (Guerriere et al., 2008).

In addition to its purchase out-of-pocket, private care is also accessed through workplace or private insurance. While some services are covered by insurance, others are not, depending on the insurance agreement. Insurance can be available through an employment package or purchased privately. Even marriage, as an institution, is part of this arrangement because health insurance can often be extended to family. There are often co-payments associated with private insurance, so individuals might still have out-of-pocket expenses associated with it.

There are also employment insurance regulations regarding medical leave. In my case, I did not have enough working hours banked in order to be eligible for employment insurance benefits as a full-time student and part-time employee at the university. My insurance through the university did not cover the use of NPWT, which meant I would need to pay for it myself.

Care taking place in domestic spaces is an important feature of privatization. There is a shift away from publicly funded care taking place in institutional spaces with publicly funded equipment to its emergence in private home spaces and spaces of care paid for by individuals and families. Our stories of building and reorganizing domestic space point to the ways in which home health care is organized and disorganized. Informal care is increasingly taking place in the home. Informal caregiving also includes accessing and coordinating services on behalf of patients who are not able to do it themselves (Hollander, Liu, & Chappell, 2009; Peckham, Williams, and Neysmith, 2014; Williams, Peckham, Rudoler, Watkins, & Tam, 2013) and the alteration of the home environment.

Being home soon after surgery can mean that individuals must adapt the home environment in order to create accessibility within the home. We rearranged our home spaces, repurposed objects, and purchased and rented assistive devices and equipment in order to accommodate for our altered embodiment. At home we become responsible for creating a space that we could navigate with changing embodiment post-operatively. Individuals and families are resourceful in regards to mending deficiencies in care.

Liz's partner built a ramp out of plywood in order to accommodate her changing mobility post-operatively. She was not able to bear weight when she was discharged from hospital and her home space was not set up for her altered mobility post-operatively. She was not aware that she would need a ramp to enter and exit her home until the day she was discharged home from hospital. As a result, she and her family mended fault lines by researching options available that would help to accommodate for her changing mobility. Liz's partner built a ramp out of plywood and wood and was able to find a business that offers rentals of wheelchairs. The combination of the ramp and wheelchair made it possible for her to get into her home upon discharge from hospital.

Private homes are often not set up for surgical recovery or changing embodiment. Our stories reveal the inventiveness of mending fault lines—using stacks of books and boxes to accommodate for changing embodiment and building a ramp out of plywood and screws. The larger relations, including organizational and legislative arrangements, that create circumstances where families need to fill in gaps in care apply to everybody. We 'made do' by repurposing objects to use as mobility aids and by rearranging objects for ease of access within our homes and communities. Objects actively take part in shifting relations and help to produce enabling or disabling arrangements (Hall & Wilton, 2017). For example, my father found a way to make my computer accessible to me by adapting my desk with an upside-down drawer.

Participants and families rearranged their homes so that they would not need to use the stairs. Liz moved her bedroom furniture onto the main level of her home in order to avoid stairs. My family members moved a bed from a spare bedroom into my family room so that I could be comfortable while I healed and be in the centre of the home.

While Liz and I were able to reorganize our homes in ways that gave us a place to rest within the centre of the home, individuals might not have the familial support and material resources available to help them reorganize the home and build in ways that enable access. Recovering in the community poses additional challenges for individuals who rent or have insecure housing. They might not be able to modify the domestic space in which they are living in order to create access.

The ways in which we mended fault lines through repurposing items, such as using shopping carts as mobility aids, and recruiting assistance from friends and family, brings to light how we participate as active agents in both the management and implementation of our care. In many ways, we challenge the construction of ourselves as passive patients or objects of the health system by becoming active participants in our care through creating spaces and supports we are able to navigate and to help to make our homes accessible to us post-operatively.

Conclusion

Austerity measures have led to growing familial responsibility for providing care and absorbing the costs associated with private care and equipment (England, 2010; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002). Individuals are forced to rely on family or friends for care or to purchase care through private channels or insurance co-payments. Our narratives point to the ways in which we mended fault lines in formal care arrangements by organizing informal care and purchasing care out-of-pocket.

While care is increasingly privatized, little is known about the extent to which individuals and families manage informal and private care in the home (Yu, Guerriere, & Coyte, 2015). Our narratives shed some light on how individuals cope with the privatization of care in various ways. We managed informal and private arrangements in order to care of ourselves and mend fault lines in the public care system. Care becomes an extension of familial responsibilities as it increasingly takes place in the home (Milligan & Power, 2009). Family and friends provided us with informal support when it was needed and helped to create a home environment that we could navigate.

Participants used objects, like shopping carts as mobility aids, and made bandages that were much too large smaller with scissors and tape. Participants and I created alternative aids and devices when these were not readily available to us through the public health system. We talk about how we altered our home spaces and repurposed objects in order to accommodate for changing embodiment; we ‘made do’ by using objects we had around the house or the community to aid with our mobility at home and access places outside of the home.

We repurposed items for other uses and reorganized our homes to accommodate our changing mobility; our friends and family provided care by repurposing and building to create a place where we could heal comfortably. Family members reorganized and restructured, and sometimes even relocated, in order to create homes that could be easily navigated by family members.

The reduction in government spending has helped to shift care from the public health system to individuals and has increased familial responsibility for, and costs associated with, care in the home and community (England, 2010; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002). Our narratives of mending fault lines highlight deficiencies in formal care arrangements and the various ways in which individuals and families manage these shortfalls.

CONCLUSION

The purpose of this study is to further our knowledge of care from the perspective of patients. In the previous three chapters of this dissertation, I have explored patient experiences of health care, including my own as a patient researcher, and examined the ways in which care is shaped by the broader socio-political landscape of care. The health system, made up of public, private, informal, and third sector arrangements, is in flux. Over the past few decades, governments have put in place neoliberal reforms that increasingly shift the responsibility for care from the public to the private domain. While the cost of care is increasing due to medical advances, an aging population, and inflation, public financing for health care is decreasing (Block, 2018). These changes impact where care takes place and who provides care; as care is shifted to the home, a growing proportion of care work is performed by family members.

In this chapter, I explore the implications of this study. I begin by providing a discussion of the main findings and analysis. I then explore the substantive contributions of my work to the care literature and discuss how this study relates to health care policy and practice. Finally, I outline potential avenues for research.

Summary of Findings

First, I return to my research questions, centered around what it means to receive care in the broader care system and how experiences of care are shaped. These include: (1) What are patients' embodied experiences of care? (2) How do carers, both paid and unpaid, help shape experiences of care? (3) How do policies and processes, and the bodies that govern these, help shape care?

I use qualitative methods to examine care in Ontario, Canada, from the perspective of patients. I use auto/ethnography to explore my personal accounts of care as a patient researcher as well as my interviews with seven individuals who have undergone hip or knee replacement surgery and two daughters of these participants. My analysis reveals the struggles we face in our immediate experience of post-operative care and changing embodiment, and the ways in which these are linked to, and shaped by, the broader social organization of care. The shifting socio-political landscape of care shapes conditions of labour for health care workers (Yakerson, 2019; Zeytinoglu, Denton, Plenderleith, & Chowhan, 2015), the state of care for patients (Whiteside, 2009), and encounters of care between patients and health care workers (Hall & Wilton, 2017). In recent years, austerity measures have contributed to the informalization and privatization of care, with concurrent underfunding and understaffing of public care systems, which, in turn, translates into insufficient care being provided to patients and added pressure for individuals and families to organize their own care through informal and private care arrangements.

In chapter four, "Being Patient," our narratives point to the ways in which we are "patients" in terms of the way that we are defined by the health system and expected to be "patient" while we wait for care to take place. In my analysis, I explain that these expectations are partly shaped by broader care relations. One example is that many of our narratives point to extended wait times for care in hospital and at home. As austerity measures cut funding, and staffing is reduced, nurses' caseloads become heavier while those in receipt of care are expected to be more "patient" patients.

In chapter five, "Negotiating Care," I explore our stories of care encounters within the context of the broader care system, revealing the constraints that health care workers must operate within. The restructuring of the health system has created poor working conditions for nurses and limitations in terms of what they can and cannot do for patients. As my analysis demonstrates, these broader changes contribute directly to the tensions that shape the intimate encounters of care within hospital wards and people's homes.

In chapter six, "Mending Fault Lines," my analysis highlights the growing familial responsibility for providing care and absorbing the costs associated with private care and equipment (England, 2010; Milligan & Power, 2009; Power & Hall, 2018; Williams, 2002). At the same time, the analysis directs attention to our creative capacity, as we seek to find ways to mend fault lines in the public care system. Our stories reveal various ways in which individuals and families manage and struggle within the confines of the system in place. Individuals and families build, rearrange, reorganize, and struggle to make care work. My data picks up our individual and personal experiences and difficulties, and my analysis transforms these into socio-political issues by highlighting how experiences are shaped by the broader political and organizational arrangements.

Contributions

In this section, I outline the empirical, methodological, and conceptual contributions my study makes to the current literature, and consider the implications of this study for policy and practice.

Lived Experience

While reviewing the care literature, I came to realize that my experience of care was not adequately reflected in the existing scholarship. The perspective of care recipients is underrepresented in literature (Daly, 2013; Dossa, 2005; Hande, 2017; Kelly, 2016; Morris, 1995; Wiles, 2011). While the use of narratives and lived experience of receiving care have grown in geography in more recent years (De Leeuw, Parkes, Morgan, Christensen, Lindsay, Mitchell-Foster, & Jozkow, 2017), positive experience dominates these accounts, with little critique of the political climate in which care takes place (Atkinson et al., 2015). The same is true of disabled people, who are often excluded from feminist care scholarship (Daly, 2013; Dossa, 2005; Hande, 2017; Kelly, 2016; Morris, 1995; Thomas, 2001a). When attention is paid to disabled people and care recipients in these literatures, they are often portrayed in a negative light (Hansen, Hanes &

Driedger, 2018; Wiles, 2011). They are often presented as being the tragic victims of circumstance (Hansen, Hanes & Driedger, 2018). For instance, they are depicted as passive, frail objects, or constructed as dependent, rather than as thinking and feeling beings participating in the research (Morris, 1995; Wiles, 2011).

There is a need to explore care from the perspective of individuals who have been marginalized or underrepresented in the care literature (Daly, 2013, Dossa, 2005, Hande, 2017; Kaley, Hatton & Milligan, 2019; Kelly, 2016; Morris, 1995; Power & Hall, 2018 & Wiles, 2011). More recently, Yu, Guerriere, and Coyte (2015) have argued for greater attention to the ways that individuals and families manage informal and private care. In times of austerity, individualism, and commodification, there is a growing need for research seeking to understand care (Power & Hall, 2018).

My research addresses these calls to action by using narratives of lived experience of care as an important source of data. Feminists have long advocated for the inclusion of lived experience in research (Butz and Besio, 2004; Morris, 1992; Moss, 2001; Perreault, 1995). Narratives can be used to reclaim experiences that have been previously misrepresented (Mintz, 2007; Perreault, 1995) and lived experience helps to shed light on what it means to be a patient in the healthcare system (Wiles, 2011).

My study sheds light on how individuals cope with the privatization of care by managing informal and private care arrangements in order to mend fault lines in the public care system. One example is from chapter six, “Mending Fault Lines,” when our narratives point to the ways in which individuals and families try to mend deficiencies in care in various ways. Family and friends provided us with informal care and support when it was needed and helped to create a home environment that we could navigate. Participants used objects like shopping carts as mobility aids, and we created alternative aids and devices when these were not readily available to us through the public health system. In this study, participants emerge as actively engaged in the relational work of care.

Our stories also point to the ways in which patients advocate for themselves and push back against expectations placed upon them. One example is when participants made noise and yelled to get the attention of care providers or contacted managers when unsatisfied with the care provided. In this sense, my research helps to complicate constructions of patients as dependent and not involved in care by highlighting the creative, relational work that patients undertake in their efforts to access and manage care.

My study is in line with and builds upon feminist ethics of care scholarship, focusing on the specifics of daily interactions (Barnes, 2012) and seeking to understand the meaning and impact of care. Feminist disability scholars have explored embodied dimensions of care (Hande, 2017) (see Morris, 1995; Thomas, 2001a). Personal narratives offer deep insights into how people experience and understand care (Atkinson & Rubinelli, 2012). My research builds on this literature, revealing that our stories are practically significant because they indicate areas related to health care that need improvement (such as access to assistive devices and personal care) and also politically valuable because they provide a way to enable patient voice and legitimize experiential knowledge (Atkinson & Rubinelli, 2012).

Methodology

Part of my contribution to the literature is that I have incorporated my voice as a patient researcher receiving care. I chose auto/ethnography because personal stories of care draw the reader in and help them to become connected to, and understand, the patient perspective on care. The voice of the researcher helps readers to imagine themselves having lived this experience (Morris, 2001).

De Leeuw et al. (2017) note that over the past decade, geographers have increasingly been using more self-reflective and creative methods in research. They call for more “unscripted” methods and methodologies, where dialogue and activities are unplanned. They also argue that research must be taken up with critical analytic reflection (De Leeuw et al., 2017).

My research methodology responds to these calls to action. My use of auto/ethnography advances the use of self-reflective and unscripted methods and critical analytic reflections. Auto/ethnography is a qualitative and systematic methodology (Frankhouser & Defenbaugh, 2017) in the sense that it has both storytelling features and opportunity for critical analysis (Chang, 2008). My position as a patient researcher using auto/ethnography provides a unique perspective and opportunity for analysis. I collected data spontaneously while receiving care as a patient. My interactions with health care workers and other patients and my observations within the health system were unplanned. I share thick and rich descriptions in terms of my ethnographic observations and my personal auto/ethnographic accounts of my experience receiving care as a patient. I provide a critical analysis by interpreting our stories within the context of the broader socio-political system. In this sense my position as a patient researcher is both unique and complicated because I write and analyze data both as a patient and as a critical scholar.

Auto/ethnography provides an important opportunity for what Donovan and Moss (2017) call 'writing intimacy'. This term refers to finding connections that resonate in our research in order to support broader political projects (Donovan & Moss, 2017). These authors define intimacies in geography as engaging in research, telling personal stories, exploring intimacies between participants, and gathering information about participants. It requires that we recognize interconnectedness and broader social relations (Donovan & Moss, 2017). While I begin from personal stories, auto/ethnography allows me to connect these intimate experiences to the broader socio-political landscape, in line with political ethics of care scholarship. I draw links between the personal and wider processes that help to contest multi-scaled arrangements of power (Butz & Besio, 2004; Donovan & Moss, 2017; Moss, 2001).

In the research, I used multiple means of data collection, which is common amongst auto/ethnographers (Chang, 2008; Frankhouser, & Defenbaugh, 2017). This study makes some distinctive contributions in terms of the methods used for data collection. I incorporated formal interviews with participants, informal interviews with other patients and health care workers, personal journaling, observation and fieldnotes, and my patient records and emails sent amongst my care providers. Few researchers have used their own medical records (see Greenhalgn, 2001), and I did not find other studies examining emails sent amongst care providers as a source of data. Accessing these records proved arduous; however, they proved to provide unique insight into care encounters and relations. My personal health records, particularly the emails I had access to, provide important insight into the perspective of care providers in terms of how they viewed me as a patient, as well as the broader organizational response that takes place when a complaint is made.

Conceptualizing Care

One strength of my work is that I am thinking about care both practically as well as relationally (Grant et al., 2004; Kelly, 2016; Milligan & Wiles, 2010; Tronto, 1993). In line with geographies of care and feminist ethics of care, I approach care from the position that individuals are interdependent and that care is relational, in the sense that it is influenced by multiple broader forces (Milligan & Wiles, 2010) and is embodied and emotional (Power & Hall, 2018; Wiles 2011).

My relational approach to care is in line with geographers who note that bodies, objects, and space come together in shifting relations to create lived experiences of the social world (Hall & Wilton, 2017). This approach recognizes that health, care, space, illness, and disability are constructed in relation to one another. I understand care as connected to how people relate to one another, history, and the broader landscape of care.

I think of care in terms of reorganizing, grocery shopping, cooking, cleaning, financial transactions, exchanges between care workers and patients, and the rearranging and assisting that are part of formal and informal care arrangements, rather than merely referring to more formal care work like dressing changes. Milligan and Wiles (2010) define care similarly as not strictly about caring about or caring for another person, but also as bathing, dressing, preparing meals, shopping, managing finances, and other everyday acts that encompass practical and emotional support. My conceptualization of care also takes into account Kelly's (2016) definition of accessible care, understanding care in various ways, including as a tension in the sense that it can be a form of oppression or an attitude.

Connecting to Broader Relations

Recent geographies of care have developed in response to the care crisis and the political circumstances surrounding care (Milligan & Power, 2009; Power & Hall, 2018). The care crisis involves the rising costs of care, decreasing quality and quantity of publicly funded care, and poor working conditions for health care workers (England, 2010). Currently, geographers are particularly interested in how austerity measures help to shape support provisions (Power & Hall, 2018) and how the shifting neoliberal landscape of care means that care is increasingly taking place in the home (England, 2010; Power & Hall, 2018; Williams, 2002). Geographies of care have demonstrated that the landscape of care is continually changing as care is reformed through cuts to public financing for health care (Power & Hall, 2018). These ongoing transformations in the system suggest that research in this area is timely and significant. While this area is an important focus for geographers, Atkinson et al. (2015) note that among the narratives about illness and care, there is minimal critique of the political climate that surrounds such experiences. Geographers call for research that explores subjective perspectives on health and health care experience (Atkinson et al., 2015) and for critical scholarship exploring how neoliberal austerity measures have impacted care (Power and Hall, 2018).

In this sense, my study provides a unique lens for readers, helping to build knowledge of what it means to be a patient in an increasingly neoliberal landscape of care. The research helps to fill gaps in knowledge by critically engaging patients’ experiences and perspectives, and by analyzing our narratives in the context of the wider conditions that help to shape care. I explore how people try to manage within this fragmented system of care. My analysis sheds light on the constraints under which health care workers are operating and patients are receiving care.

Researchers argue that the health care system in Canada is moving towards a two-tiered system of public and private care through increased access to medical tourism, subcontracting, private care facilities, and fundraising efforts (Whiteside, 2006; 2011). I build upon this knowledge, exploring lived experiences of care with a critical lens concerned with the informalization and commodification of care (Cox, 2013). I consider how our encounters are impacted by these larger factors, such as access to medical tourism in the face of funding cuts and long wait lists for care in Canada.

Implications for Health Care Policy and Practice

While the purpose of this project was not to explore policies in depth, my findings have important implications for health care policy and practice. This research is timely given the current emphasis on person-centered care within the medical community (Atkinson & Rubinelli, 2012). Those who work in health care are required to have narrative competency with respect to having the ability to listen to patient voices (Atkinson & Rubinelli, 2012). This research sheds light on patient experiences of care and could provide insight into care encounters and relations for care providers regarding how care is experienced and represented, how care is shaped, and how care is understood from a patient perspective.

Our stories are not only valuable for researchers and clinicians, but also for other Canadians because care is something everyone has experienced or will experience a need for at some point in their lives. Our narratives help to reveal what individuals might expect in terms of availability of support for their needs pre- and post-operatively. In particular, the research sheds light on disparities within the health care system as the privatization and informalization of care means that not all Canadians will have access to the same level of care—those who can afford to purchase private care may do so, while others must struggle to attain publicly funded care. Not all Canadians have the financial means to rent or purchase equipment and such equipment is not always provided to home care recipients. Perhaps if governments began reinvesting in health care, rather than making funding cuts, some of these difficulties might be mitigated.

As care is shifted to the home, we need to think about how domestic space is (re)organized. Our stories reveal that the architecture of our homes and communities does not always work well for people receiving care. Our stories of mending fault lines reveal that people with changing embodiment are having trouble navigating their homes and that individuals and families are attempting to reorganize and rearrange the home space to make it more physically accessible. Homes are not often constructed in a way that takes into account varying embodiment and accessibility. Our bodies change as we age, and as our embodiment changes the home becomes more difficult to navigate. But what if we thought about how the home is built and organized in terms of receiving care at home? If homes were built with the understanding that bodies age and embodiment changes over the life course, then houses might be more flexible in terms of accessibility. Apartment buildings might have level-entry balconies and evac chairs[11] in the stairwells. Neighbourhoods would have more level-entry homes throughout. Children and adults who use wheelchairs, walkers, and other mobility devices could visit friends' houses.

Implications for Future Research

This work is an important starting point from which further research could explore lived experiences of health care as the landscape of care continues to change. Care experiences vary widely and cannot all be reflected here because our stories focused specifically on care related to surgery and my sample does not represent all people receiving care in Canada. Further research could explore the patient experience of care under various circumstances other than pre- and post-operative care. Care provisions and access to care can vary widely for a host of reasons, such as where care takes place, the medical treatment needed and received, the supports and services needed, level of mobility for care receivers, access to informal and private care arrangements, and private insurance. Thus, patient experience can vary significantly, and therefore

---

[11] An evac chair is an emergency stairway exit device for individuals with decreased mobility or who use a wheelchair. This chair makes it possible for someone to safely exit a building in the case of a fire or to evacuate with the assistance of another person.

additional research that explores various patient perspectives on care could provide further insight into the patient experience and the impact of care relations.

There is a need for a more intersectional approach to research, thereby exploring gender, race, and culture in terms of receiving and providing care. Exploring how newcomers to Canada experience care within this shifting landscape is one example of potential future research in this area. Research examining issues that employees face, including gendered, racialized, and oppressive forms of work and the possibility of abuse in the employer/employee relationship, is not often explored within disability studies and geographies of care literatures (Connell & Walton-Roberts, 2016; Kelly, 2016). While I have tried to engage with feminist ethics of care scholarship to recognize the ways in which the labour of nurses is impacted by neoliberalism, future work could usefully combine a care worker perspective alongside that of care recipients to explore the relational (and gendered and racialized) dimensions of care in more depth. Such work could provide an opportunity to create knowledge of the system and of care from various perspectives, which might also help to shed light on the constraints under which individuals are working within the health system.

Two family members took part in this study by joining interviews with their parents, and their contributions provided insight into the ways in which families try to manage within the health system by providing informal care and arranging private care. This perspective is under-researched in the current care literature

(Smith-Carrier et al., 2018). Further research exploring the experiences and perspectives of informal carers and family members could provide a unique lens into care and the care system and help to shed light on the impact of the changing system on informal carers and family.

Summary

As a society in Canada our health system is viewed with a sense of pride. We believe we have a social contract whereby care is universal and an understanding prevails that our health system in one of the best available. However, what we are experiencing is the destruction of this social contract since publicly funded care is being withdrawn as care is increasingly informalized, privatized, and commodified.

Currently, Premier Doug Ford and his Conservative cabinet are increasingly privatizing care in Ontario through neoliberal austerity measures that cut public funding to health care in an attempt to balance budgets. The weight of precarious working conditions and workloads is going to get heavier and care needs more difficult to fulfill because of these measures. As care is increasingly informalized and privatized, individuals will be forced to rely more heavily on family members for providing informal care or will have to purchase care privately out-of-pocket or through insurance co-payments. The working conditions of nurses will continue to deteriorate. It will become increasingly more difficult to mend fault lines in the system.

The way care is arranged applies to, and impacts, everyone. While our narratives reveal our personal experiences of care, the conditions in which they took place apply to everyone because, while individual care workers and patients change, the broader socio-political landscape continues to shape care encounters and the working conditions of health care workers. At some point, everyone will need access to the health system with the same systematic issues: restricted access to mobility devices and medical equipment, the prolonged time it takes nurses to provide care, and the need to purchase care privately or mend deficiencies using informal carers.

My research has shown the importance of exploring lived experience of care from the perspective of care receivers. Our stories help to reveal what it means to be a patient in the current health system and provide important insight into how individuals manage informal and private care arrangements in order to mend fault lines in the public care system. My analysis focuses on how care takes place within the context of the broader health system and how encounters are shaped by a wide range of organizational and legislative arrangements dominated by neoliberalism. Reforms lead to major changes in the health system (Sakellariou, & Rotarou, 2017) and impact the way care is organized and delivered. Research in this area is significant given these current reforms because it helps to reveal the impact and potential further consequences of austerity.

REFERENCES

Agnew, J. A. (1987). Place and politics: The geographical mediation of state and society. Boston, MA: Allen & Unwin.

Atkinson, P. and Delamont, S. (eds) (2006). Narrative methods, Volume 1. London, UK: SAGE Publications.

Atkinson, R. (2006). The life story interview as a bridge in narrative inquiry. In J. Clandinin (Eds.), Handbook of Narrative Inquiry: Mapping a Methodology (224-245). Thousand Oaks, CA: SAGE Publications.

Atkinson, S., Evans, B., Woods, A., and Kearns, R. (2015). 'The medical' and 'health' in a critical medical humanities. *Journal of Medical Humanities. 36(1*), 71.

Atkinson, S., & Rubinelli, S. (2012). Narrative in cancer research and policy: voice, knowledge and context. Critical Reviews *in Oncology/hematology*, *84*(02), S11–S16.

Attree, M. (2001). Patients' and relatives' experiences and perspectives of 'good' and 'not so good' quality care*. Journal of Advanced Nursing, 33(4),* 456-466.

Baines, D. (2004). Seven kinds of work – only one paid: Raced, gendered and restructures work in social services. *Atlantis, 28*(2), 19-28.

Baines, D., & Cunningham, I. (2015). Care work in the context of austerity. *Competition & Change, 19*(3), 183–193.

Barker, L. M., & Nussbaum, M. A. (2011). Fatigue, performance and the work environment: A survey of registered nurses. *Journal of Advanced Nursing, 67*(6), 1370-1382.

Barrett P, Hale B, Butler M. (2014). Family care and social capital: Transitions in formal care. Dordrecht, NL: Springer.

Barnes, M. (2012). Care in everyday life: An ethic of care in practice. Bristol, UK: The Policy Press.

Barua, B. & Ren, F. 2015). Leaving Canada for medical care. Fraser Research Institute. Retrieved November 16th, 2019 from https://www.fraserinstitute.org/sites/default/files/leaving-canada-for-medical-care-2015.pdf

Beauvoir, S. (1949). *The Second Sex.* Harmondsworth, Middlesex, U.K. : Penguin Books

Berry, L., Curry, P., (2012). Nursing workload and patient safety: Understanding the value of nurses, the effects of excessive workload, and how nurse-patient ratios and dynamic staffing models can help. Ottawa, ON: Canadian Federation of Nurses Unions. Retrieved September 5th, 2019 from: https://nursesunions.ca/wp-content/uploads/2017/07/cfnu_workload_printed_version_pdf.pdf

Block, S. (2018). Nurses work deserves attention during the Ontario election. (Canadian Center for Policy Alternatives.) Retrieved December 2nd, 2019 from http://behindthenumbers.ca/2018/05/09/nurses-work-deserves-attention-during-the-ontario-election/

Blunt, A. & Dowling, R. (2006). Home. New York, NY: Routledge.

Bond, M.A., Punnett, L. Pyle, J.L., Cazeca, D. & Cooperman, M. (2004). Gendered work conditions, health, and work outcomes. *Journal of Occupational Health Psychology, 1*, 28–45

Bradshaw, M. & Stratford, E. (2010). *Qualitative Research Design and Rigour*. Oxford, UK: Oxford University Press.

Brannelly, T. (2018). An ethics of care research manifesto. *International Journal of Care and Caring, 2*(3), 367-378.

Brown, L. & Barnett, J. (2004). Is the corporate transformation of hospitals creating a new hybrid health care space? A case study of the impact of co-location of public and private hospitals in Australia. *Social Science & Medicine, 58,* 427-444.

Butz, D and Besio, K. (2004). The value of ethnography for field research in transcultural settings. *The Professional Geographer, 56*(3), 350-360.

Cameron, D. (1995). *Feminism and Linguistic Theory.* London: MacMillan Press.

Cameron, K. (2008). *Unpacking Disability Through Healthcare*. (Unpublished undergraduate capstone project). Ryerson University, Toronto, ON.

Cameron, K. (2010). *Navigating Access to Homecare: Narratives and Patient Literature.* (Unpublished master's thesis). York University, Toronto, ON.

Canada Health Act, R.S.C. 1985, c.C-6. S. 1-15.

Canadian Institute of Health Information. (2017). Joint replacements. Retrieved November 9th, 2019 from https://www.cihi.ca/en/joint-replacements

Canadian Institute for Health Information. (2019). Home care. Retrieved January 2nd, 2020 from https://www.cihi.ca/en/home-care

Canadian Joint Replacement Registry. (2014). Hip and knee replacements in Canada, 2013–2014: Canadian Joint Replacement Registry Annual Report. Retrieved November 18th, 2018 from https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC2945

Canadian Joint Replacement Registry. (2019). Report: Hip and Knee replacement in Canada. 2017-2018. Retrieved Dec 1st, 2019 from https://www.cihi.ca/en/hip-and-knee-replacements-in-canada-cjrr-report-0

CBC. (2019, April 12). What Ontario's plan to reduce public health units could mean. Retrieved December 2nd, 2019 from https://www.cbc.ca/news/canada/london/ontario-middlesex-london-health-unit-ontario-budget-1.5094968

Chang, H. (2008). *Autoethnography as Method*. Walnut Creek, CA: Left Coast Press.

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine, 49*(5), 651-661.

Charlton, J. I. (1998). *Nothing about us without us : Disability oppression and empowerment*. Berkeley, CA: University of California Press. Retrieved from http://search.ebscohost.com.libaccess.lib.mcmaster.ca/login.aspx?direct=true&db=nlebk&AN=6891&site=ehost-live&scope=site

Church, K. (1995). *Forbidden Narratives: Critical Autobiography and Social Science*. New York, NY: Routledge.

Civan A, Pratt W. (2007, October). Threading together patient expertise. *AMIA Annual Symposium Proceedings*. Amia Symposium. 140-144.

Clandinin, D. J., & Connelly, F. M. (1994). Personal experience methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 413-427). Thousand Oaks, CA: SAGE Publications.

Cloutier-Fisher, D. & Joseph, A. (2000). Long-term care restructuring in rural Ontario: Retrieving community service user and provider narratives. *Social Science & Medicine, 50*(7-8), 1037-1045.

Cohen, M., Kahn, D. & Steeves, R. (2000). *Hermeneutic phenomenological research: A practical guide for nurse researchers.* Thousand Oaks, California: SAGE Publications.

Connell, J. (2006). Medical tourism: Sea, sun, sand and ... surgery. *Tourism Management, 27*(6), 1093-1100.

Connell, J., & Walton-Roberts, M. (2016). What about the workers? The missing geographies of health care. *Progress in Human Geography, 40*(2), 158-176.

Cox, R. (2010). Some problems and possibilities of caring. *Ethics, Place and Environment 13*(2),1–18.

Cox, R. (2013). Gendered spaces of commoditised care. *Social & Cultural Geography, 14*(5), 491-499.

Crooks, V.A., Kingsbury, P., Snyder, J., & Johnston, R. (2010). What is known about the patient's experience of medical tourism? A scoping review. *BMC Health Services Research, 10*(266).

Davis, L J. (1995). *Enforcing normalcy: Disability, deafness, and the body.* New York, NY: Verso.

Daly, T. (2013) Imagining an ethos of care within policies, practices, and philosophy. In P. Armstrong & S. Braedley (Eds.), *Troubling care: Critical perspectives on research and practice* (33-46). Toronto, ON: Canadian Scholar's Press.

Day, S. (2013). The implications of conceptualizing care. In P. Armstrong & S. Braedley (Eds.), *Troubling care: Critical perspectives on research and practice* (21-31). Toronto, ON: Canadian Scholar's Press.

DeFalco, A. (2016). *Imagining care: Responsibility, dependency, and Canadian literature.* Toronto, ON: University of Toronto Press.

De Leeuw, S., Donovan, C., Shafenacker, N., Kearns, R., Neuwelt, P., Merill Squier, S., McGeachen, C., Parr, H., Frank, A.W., Coyle, L.A., Atkinson, S., El-Hadi, N., Shklanka, K., Shooner, C., Beljaars, D., & Anderson, J.

(2018). Geographies of medical and health humanities: A cross-disciplinary conversation. *GeoHumanities, 4* (2), pp. 285-334.

De Leeuw, S., Parkes, M.W., Morgan, V.S., Christensen, J., Lindsay, N. Mitchell-Foster, K., & Jozkow, J.R. (2017). Going unscripted: A call to critically engage storytelling methods and methodologies in geography and the medical – health sciences. *The Canadian Geographer, 61*(2), 152-164,

Denton, M., Zeytinoglu & Davies, S. (2003). *Organizational Change and the Health and Well-being of Home Care Workers. Final Report*. Submitted to Workplace Safety and Insurance Board.

Denton, M., Zeytinoglu, I. U., Davies, S., & Hunter, D. (2006). The impact of implementing managed competition on home care workers' turnover decisions. *Healthcare Policy*, *1*(4), 106– 123.

Department of Health. (2001). The expert patient: A new approach to chronic disease management in the 21st century. London: Stationery Office.

Dierckx de Casterle, B., Verhaeghe, S. T. L., Kars, M. C., Coolbrandt, A., Stevens, M., Stubbe, M., Deweirdt, N., Vincke, J. & Grypdonck, M. (2011). Researching lived experience in health care: Significance for care ethics. *Nursing Ethics, 18*(2), 232-42.

Donovan, C. (2014). Representations of health, embodiment, and experience in graphic memoir. *Configurations, 22*(2), 237-253,304.

Donovan, C. & Moss, P. (2017). Muddling Intimacy methodologically In Moss, P. & Donovan, C. (Eds). *Writing intimacy into feminist geography*. New York, NY: Routledge.

Dossa, P. (2005). Racialized bodies, disabling worlds: “They [service providers] always saw me as a client, not as a worker”. *Social Science and Medicine, 60*(11), 2527-2536.

Drew, S. (2005). The delta factor: Storying survival and the disjunctive between public narratives and personal stories of life after cancer. *Storytelling, Self, Society, 1*(2), 76-102.

Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists’ cultural competence using disability language. *American Psychologist, 70*(3), 255-264.

Eggleton, K., Kearns, R., and Neuwelt, P. (2017). Being patient, being vulnerable: Exploring experiences of general practice waiting rooms through elicited drawings. *Social & Cultural Geography, 18*(7), 971–993.

Ellis, C. (1995). *Final negotiations: A story of love, loss and chronic illness.* Philadelphia, PA: Temple University Press.

Ellis, C. S. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: AltaMira Press.

Ellis, C. Adams, T.E. & Bochner, A.P. (2011). Ethnography: An Overview. *Forum: Qualitative Social Research, 12*(1).

England, K., Eakin, J., Gastaldo, D., & McKeever, P. (2007). Neoliberalizing home care: managed competition and restructuring home care in Ontario. In K. England & K. Ward (Eds.), *Neoliberalization: Networks, states, peoples* (169–194). Oxford, England: Blackwell.

England, K. (2010). Home, work and the shifting geographies of care. *Ethics, Place and Environment, 13*(2), 131-150.

Fetscherin, M., & Stephano, R. (2016). The medical tourism index: Scale and development validation. *Tourism Management, 52,* 539-556.

Finkelstein, V. (1998). Re-thinking care in a society providing equal opportunities for all, Discussion Paper prepared for the World Health Organization. Milton Keynes: Open University.

Fitzpatrick, K. & Neis, B. (2015) On the move and working alone: Policy implications of the experiences of unionised Newfoundland and Labrador homecare workers, policy and practice. *Health and safety, 13*(2), 47-67.

Fogarty, C., & Cronin, P. (2008). Waiting for healthcare: A concept analysis. *Journal of Advanced Nursing, 61*(4), 463-471.

Forbes, D., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D., Henderson, S., Leipert, B., & Jansen, L. (2008). Availability and acceptability of Canadian home and community-based services: Perspectives of family caregivers of persons with dementia. *Home Health Care Services Quarterly, 27*(2), 75-99.

Frank, A. (1993). The rhetoric of self-change: Illness experience as narrative. *The Sociological Quarterly, 34(1), 39-52.*

Frank, A. W. (2000). Illness and autobiographical work: Dialogue as narrative destabilization. *Qualitative Sociology, 23*(1), 135-156.

Frank, G. (2000). *Venus on Wheels*. Los Angeles, CA: University of California Press.

Frankhouser, T. L., & Defenbaugh, N. L. (2017). An Autoethnographic examination of postpartum depression. *Annals of family medicine*, *15*(6), 540–545.

Freund, P. (2001). Bodies, disability and spaces: the social model and disabling spatial organizations. *Disability & Society, 16*(5), 689-706.

Garland-Thomson, R. (2005). Feminist disability studies. *Journal of Women in Culture and Society, 30*(2), 1557-1587

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Gilligan, C. (2013). *Caring democracy: Markets, equality and justice*. New York, NY: New York University Press.

Gleeson, B. (1999). *Geographies of disability*. London, UK: Psychology Press.

Government of Canada. (2019). A prescription for Canada: Achieving pharmacare for all. Final report of the Advisory Council on the implementation of national pharmacare. Retrieved December 14th, 2019 from https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/implementation-national-pharmacare/final-report.html#3.2

Government of Ontario. (2014). Home and community care: How to get help for patients and seniors who need support living at home. Retrieved December 30th, 2019 from https://www.ontario.ca/page/homecare-seniors

Government of Ontario. (2019). Get coverage for prescription drugs. Retrieved December 16th, 2019 from https://www.ontario.ca/page/get-coverage-prescription-drugs

Grant, K. R., Amaratunga, C., Armstrong, P., Boscoe, M., Pederson, A., & Willson, K. (Eds.). (2004). *Caring for/caring about: Women, home care, and unpaid caregiving.* Aurora, ON: Garamond Press.

Grant, K. & Church, E. (2015). No place like home? Investigating Ontario's home care short comings. *The Globe and Mail.* Retrieved October, 24th, 2019 from https://www.theglobeandmail.com/news/national/no-place-like-home-investigating-ontarios-home-care-shortcomings/article25409974/.

Gray, J. (2000). Home care in Ontario: the case for copayments. *Health Law Journal, 8,* 177-197.

Greenhalgh, S., (2001). *Under the Medical Gaze: Facts and Fictions of Chronic Pain.* Berkely, CA: University of California Press.

Guerriere, D. N., Wong, A. Y. M., Croxford, R., Leong, V. W., McKeever, P., & Coyte, P. C. (2008). Costs and determinants of privately financed home-based health care in Ontario, Canada. *Health & Social Care in the Community, 16*(2), 126-136.

Gustafsson, B. Å., Heikkilä, K., Ekman, S. L., & Ponzer, S. (2010). In the hands of formal carers: Older patients' experiences of care across the perioperative period for joint replacement surgery. *International Journal of Orthopaedic and Trauma Nursing*, *14*(2), 96-108.

Hall, E., & Wilton, R. (2017). Towards a relational geography of disability. *Progress in Human Geography, 41*(6), 727-744.

Hall, S.M. (2018) The personal is political: Feminist geographies of/in austerity. *Geoforum*, 4(10).

Hammersley, M. & Atkinson, P. (1995). *Ethnography principles and practice.* New York, NY: Routledge.

Hande, M. J. (2017). *Disability (and) care in late-capitalist struggle: A dialectical analysis of Toronto-based disability (and) care activism*. (Unpublished doctoral dissertation). University of Toronto: Toronto, Ontario.

Hande, M. J., & Kelly, C. (2015). Organizing survival and resistance in austere times: Shifting disability activism and care politics in Ontario, Canada. *Disability & Society, 30*(7), 961-975.

Hanefeld, J., Horsfall, D., Lundt, N., & Smith, R., (2013). Medical Tourism: A cost or benefit to the NHS? *PLOS ONE, 8*(10), E70406

Hansen, N., Hanes, R., & Driedger, D. (2018). Introduction. In N. Hansen, R. Hanes, & D. Driedger (Eds.), *Untold stories: A Canadian Disability History Reader* (1-7). Toronto, Ontario: CSP Books Inc.

Hartzler, A., & Pratt, W. (2011). Managing the personal side of health: How patient expertise differs from the expertise of clinicians. *Journal of Medical Internet Research*, *13*(3), e62. http://doi.org/10.2196/jmir.1728

Health Quality Ontario. (2015). Measuring up 2015: A yearly report on how Ontario's health system is performing. Retrieved October 23rd, 2019 from http://www.hqontario.ca/portals/0/Documents/pr/measuring-up-2015-en.pdf

Health Quality Ontario. (2016). Wait time for surgeries and procedures. Retrieved October 13th, 2016 from https://www.hqontario.ca/System-Performance/Wait-Times-for-Surgeries-and-Procedures

Henderson, S. & Petersen, A. (2002). *Consuming health: The commodification of health.* London: Routledge.

Heyl, B. S. (2001). Ethnographic Interviewing. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, L. Lofland. (Eds.), *Handbook of Ethnography.* London, UK: SAGE Publications.

Hochschild, A. R. (2003). *The commercialization of intimate life: Home and work.* Berkeley, CA: University of California Press.

Hollander J., Liu G. , & Chappell, N. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly,12*(2), 42 -49.

Information and Privacy Commissioner of Ontario. (n.d.). Forms. Retrieved January 12th, 2020 from https://www.ipc.on.ca/guidance-documents/forms/

Jordan, J. E., Buchbinder, R., & Osborne, R. H. (2010). Conceptualising health literacy from the patient perspective. *Patient Education and Counseling, 79*(1), 36-42.

Kaley, A., Hatton, C., & Milligan, C. (2019). Health geography and the 'performative' turn: making space for the audio-visual in ethnographic health research. *Health & Place, 60,* 102210.

Kelly, C. (2016). *Disability politics and care: The challenge of direct funding.* Vancouver, BC: UBC Press.

Kittay, E. F. (1999). *Love's Labor. Essays on women, equality and dependency*. New York, NY: Routledge

Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris, 24*(1), 49-58.

Kröger, T. (2009). Care research and disability studies: Nothing in common? *Critical Social Policy, 29*(3), 398-420.

Kushner, C., Baranek, P., & Dewar, M. (2008). Home care: Change we need; Report on the Ontario health coalition's home care hearings. Retrieved December 28th, 2019 from https://www.ontariohealthcoalition.ca/index.php/home-care-change-we-need-report-on-the-ontario-health-coalitions-home-care-hearings/

Lawson, V. (2007). Geographies of care and responsibility. *Annals of the Association of American Geographers 97(*1), 1–11.

Lezzoni, L. (2012). Training physicians about caring for persons with disabilities: “Nothing about us without us!” *Disability and Health Journal, 5*(3), 136-139.

Li, L. (2009). British Columbia Osteoarthritis Survey. Retrieved July, 1st, 2018 from https://arthritis.rehab.med.ubc.ca/files/2011/08/BCOASurvey.pdf

Lim, J. (2010). Immanent politics: thinking race and ethnicity through affect and machinism. *Environment and Planning, 42,* 2393-2409.

Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York, NY: New York University Press.

Mairs, N. (1997). *Waist-high in the world: A life among the nondisabled.* Boston, MA: Beacon Press.

Martindell, D. (2012). SAFETY MONITOR: The Safe Use of Negative-Pressure Wound Therapy. *American Journal of Nursing, 112(6),* 59 – 63.

Massey, D. (2005). *For Space.* London: SAGE Publications.

McDonald, J., McKinlay, E., Keeling, S., & Levack, W. (2017). Complex home care: Challenges arising from the blurring of boundaries between family and professional care. *Kōtuitui: New Zealand Journal of Social Sciences Online, 12*(2), 246-255.

McEwan, C., & Goodman, M. K. (2010). Place geography and the ethics of care: Introductory remarks on the geographies of ethics, responsibility and care. *Ethics, Place and Environment,13*(2),103-112.

McGregor, S. (2001). Neoliberalism and health care. *International Journal of Consumer Studies, 25*(2), 82-89.

McIntosh, P. (1989). White Privilege: Unpacking the Invisible Knapsack. *Peace and Freedom Magazine.* Retrieved December 19th, 2019 from https://psychology.umbc.edu/files/2016/10/White-Privilege_McIntosh-1989.pdf

Meeks, W. (1986). A hermeneutics of social embodiment. *The Harvard Theological Review, 79*(1-3), 176-186.

Milligan, C. & Power, A. (2009) The changing geography of care. In T. Brown, S. McLafferty & G. Moon (Eds.), *A companion to health and medical geography (*567-568). Hoboken, NJ: John Wiley & Sons.

Milligan, C., & Wiles, J. (2010). Landscapes of care. *Progress in Human Geography, 34*(6), 736-754.

Mintz, S. (2007). *Unruly bodies: Life writing by women with disabilities.* Chapel Hill, NC: The University of Carolina Press.

Mirsaidi, N. (2010). Negative pressure wound therapy: Use with care. *Nursing, 40*(9), 64-66.

Morris, J. (1992). Personal and political: A feminist perspective on researching physical disability. *Disability, Handicap & Society, 7*(2), 157-166.

Morris, J. (1993). *Independent lives? Community care and disabled people.* London, UK: Macmillan Press Ltd.

Morris, J. (1995). Creating a space for absent voices: Disabled women's experience of receiving assistance with daily living activities. *Feminist Review, 50,* 68-93.

Morris, J. (1997). Care of empowerment? A disability rights perspective. *Social Policy & Administration, 31*(1), 54-60.

Morris, J. (2001). Impairment and disability: Constructing an ethics of care that promotes human rights. *Hypatia,16*(4), 1-16.

Morris, J. (2004). Independent living and community care: A disempowering framework. *Disability & Society, 19*(5), 427-442.

Moss, P. (2001). *Placing autobiography in geography*. Syracuse, NY: Syracuse University Press.

Murdoch, J. (2006). *Post-Structuralist Geography: A Guide to Relational Space.* London: SAGE Publications.

Murphy, R. (1987). *Body silent: The different world of the disabled.* New York, NY: Norton Paperback.

Navarro, V. (2007). Neoliberalism as a class ideology; Or, the political causes of the growth of inequalities. *International Journal of Health Services, 37*(1), 47–62.

Neysmith, S.M. (1991). From community care to a social model of care. In C. Baines, L. Evans, and S.M. Neysmith (Eds.), *Women's caring: Feminist perspectives on social welfare.* (pp.272-299). Toronto, ON: McClelland and Stewart.

Neysmith, S. M., & Aronson, J. (1997). Working conditions in home care: negotiating race and class boundaries in gendered work. *International Journal of Health Services*, *27*(3), 479–499.

Noddings, N. (1984). *Caring: A feminine approach to ethics and moral education.* Berkeley, CA: University California Press.

Noddings, N. (2012). The language of care ethics. *Knowledge Quest*, *40*(5), 52+.

O'Brien-Pallas L., Griffin P., Shamian J., Buchan J., Duffields C., Stone P.W. (2006). The Impact of Nurse Turnover on Patient, Nurse and System Outcomes: a pilot study and focus for a multi-center international study. *Policy Politics and Nursing Practice*, 7(3), 169-79.

Oliver, M. (1990). *The politics of disablement*. London, UK: MacMillan Press.

Ontario Health Coalition. (2010). Mission + mandate. Retrieved December 17th, 2019 from https://www.ontariohealthcoalition.ca/index.php/about-us/mission-mandate/

Ontario Health Coalition. (2019). Mounting health care cuts: List of the Ford government health care cuts to date. Retrieved December 17th, 2019 from https://www.ontariohealthcoalition.ca/index.php/update-mounting-health-care-cuts/

Ontario Home Care Association. (2011). Home care nursing in Ontario. Retrieved October 19th, 2019 from https://www.homecareontario.ca/docs/default-source/HHR/hc-nsg-in-ontario---mar-2011---final-rev.pdf?sfvrsn=8

Ontario Non-Profit Housing Association. (2018). An affordable housing plan for Ontario. Co-operative housing Federation of Canada (Ontario Region). Retrieved November 20th, 2019 from http://onpha.on.ca/Content/Advocacy_and_research/Advocacy/Affordable_Housing_Plan_for_Ontario.aspx

Ontario Nurses Association. (2017). More funding, But more RN cuts in Southwestern Ontario. *Behind the Front Lines, 9*(6), 5.

Ontario Nurses Association. (2019). About ONA: Vision, mission and history. Retrieved December 17th, 2019 from https://www.ona.org/about-ona/our-vision-mission-and-history/

Ottenberg, S. (1990). Thirty years of fieldnotes: Changing relationships to the text. In R. Sanjek (Ed.), *Fieldnotes* (pp. 139-160). Ithaca, NY: Cornell University Press.

Pascal, J. (2006). *The lived experience of cancer survival: Heideggerian perspectives* (Unpublished doctoral dissertation). La Trobe University, Australia.

Pascal, J., & Endacott, R. (2010). Ethical and existential challenges associated with a cancer diagnosis. *Journal of Medical Ethics, 36,* 279-283.

Peckham, A., Williams, A. P., & Neysmith, S. (2014). Balancing formal and informal care for older persons: How case managers respond. *Canadian Journal on Aging, 33*(2), 123-36.

Penner, J. (2014). *Anachronistic me: An autoethnographic account of recovery through volunteerism.* (Unpublished master's thesis). Brock University, St. Catherines, Ontario.

Perreault, J. (1995). *Writing Selves, contemporary feminist autography.* Minneapolis, MN: University of Minnesota Press.

Personal Health Information Protection Act, R.S.C. 2004, c. 15, Sched. 30, s. 1-8.

Pesut, B. & Thorne, S. (2019). Why people choose medically assisted death revealed through conversations with nurses. *The Conversation*. Retrieved December 4th, 2019 from https://theconversation.com/why-people-choose-medically-assisted-death-revealed-through-conversations-with-nurses-122000

Ponterotto, J. G. (2006). Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *The Qualitative Report*, *11*(3), 538-549.

Power, A., & Hall, E. (2018). Placing care in times of austerity. *Social & Cultural Geography, 19*(3), 303-313.

Price, M. (2009). *Absent Citizens: Disability politics and policy in Canada*. University of Toronto Press: Toronto, ON.

Rachlis, M. (2019, August 28). De-listing medical services is wrong diagnosis, wrong prescription for health-care system. *The Toronto Star*. Retrieved December 10th, 2019 from https://www.thestar.com/opinion/contributors/2019/08/28/de-listing-medical-services-is-wrong-diagnosis-wrong-prescription-for-health-care-system.html

Raphael, D. (2000). Getting serious about the social determinants of health: New directions for public health workers. *Health Promotion and Education, 15*(3), 15-20.

Registered Nurses' Association of Ontario. (2019). Ontario needs more RNs. Retrieved December 2nd, 2019 from https://rnao.ca/news/ontario-needs-more-rns-0

Richards, R. (2008). Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability. *Qualitative Health Research, 18*(12), 1717-1728.

Rioux, M. & Daly, T. (2006). Constructing disability and illness. In D. Raphael, T., Bryant & M. Rioux (Eds.), *Staying alive: Critical perspectives on health, illness, and health care* (305-324)*.* Toronto, ON: Canadian Scholar's Press.

Sakellariou, D., & Rotarou, E. S. (2017). The effects of neoliberal policies on access to healthcare for people with disabilities. *International journal for equity in health*, *16*(1), 199.

Saxton, M., Curry, M. A., Powers, L. E., Maley, S., Eckels, K., & Gross, J. (2001). 'Bring my scooter so I can leave you': A study of disabled women handling abuse by personal assistance providers. *Violence against Women, 7*(4), 393-417.

Shakespeare, T. (2000). *Help*. London, UK: Venture Press.

Sharif, B., Kopec, J., Bansback, N., Rahman, M. M., Flanagan, W. M., Wong, H., Fines, P. & Anis, A. (2015). Projecting the direct cost burden of osteoarthritis in Canada using a microsimulation model. *Osteoarthritis and Cartilage, 23*(10), 1654-1663.

Shaw, J., & Baker, M. (2004). "Expert patient"--dream or nightmare? *BMJ (Clinical research ed.)*, *328*(7442), 723–724.

Sjöling, R. M., Ågren, R. Y., Olofsson, N., Hellzén, R. O., & Asplund, R. K. (2005). Waiting for surgery; living a life on hold—a continuous struggle against a faceless system. *International journal of nursing studies*, *42*(5), 539-547.

Smith-Carrier, T., Pham, T., Akhtar, S., Seddon, G., Nowaczynski, M., & Sinha, S. K. (2018). 'It's not just the word care, it's the meaning of the word…(they) actually care': Caregivers' perceptions of home-based primary care in Toronto, Ontario. *Ageing and Society, 38*(10), 2019-2040.

Snyder, J., Crooks, V. A., Johnston, R., & Kingsbury, P. (2011). What do we know about Canadian involvement in medical tourism? A scoping review. *Open Medicine*, *5*(3), e139–e148.

Sorrell, J. M., & Redmond, G. M. (1995). Interviews in qualitative nursing research: Differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing, 21*(6), 1117-1122.

Stabile, M., Laporte, A., & Coyte, P. (2006). Household responses to public home care programs. *Journal of Health Economics, 25(*4), 674-701.

St-Amant, O., Ward-Griffin, C., Brown, J.B., Martin-Matthews, A. Sutherland, N., Keefe, J., Kerr, M.S. (2014). Professionalizing familial care: Examining nurses' unpaid family care work. *Advances in Nursing Science. 37*(2),117-131.

Thilina, B. (2019, May 13). Ontario public health cuts will endanger the public. *National Post.* Retrieved December 2nd, 2019 from https://nationalpost.com/pmn/news-pmn/ontario-public-health-cuts-will-endanger-the-public

Thomas, C. (2001a). Feminism and disability: The theoretical and political significance of the personal and the experiential. In L. Barton (Eds.), *Disability politics & the struggle for change (*48-58). London, GB: David Fulton Publishers Ltd.

Thomas, C. (2001b). Medicine, gender, and disability: disabled women's health care encounters. *Health Care for Women International, 22*(3), 245-262.

Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology.* New York, NY: Palgrave McMillan Press.

Thompson, W. B. (2001). Policy making through thick and thin: Thick description as a methodology for communications and democracy. *Policy Sciences, 34*(1), 63.

Thorne, S. E., Ternulf Nyhlin, K., & Paterson, B. L. (2000). Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies, 37*(4), 303-311.

Tourangeau, A.E., Cranley, L.A., & Jeffs, L. (2006). Impact of nursing on hospital patient mortality: a focused review and related policy implications. *Quality and Safety in Health Care, 15(*1), 4–8.

Tourangeau, A. E. , Patterson, E. , Saari, M. , Thomson, H. & Cranley, L. (2017). Work-related factors influencing home care nurse intent to remain employed. *Health Care Management Review, 42*(1), 87–97.

Tourangeau, A. E., Villeneuve, M., Laporte, A., & Berta, W. (2014). Examining the impact of home care nurse staffing, work environments and collaboration on patient outcomes: a scoping review of the literature. *Tourangeau Outcomes Research.* Retrieved July, 6th, 2019 from https://www.researchgate.net/publication/270451867_Examining_the_Impact_of_Home_Care_Nurse_Staffing_Work_Environments_and_Collaboration_on_Patient_Outcomes

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care.* New York, NY: Routledge.

Tronto, J. C. & Fisher, B. (1990). Towards a feminist theory of caring. In E. K. Abel & M. Nelson (Eds.), *Circles of care: work and identity in women's lives.* (35-62). Albany, NY: State University of New York Press.

Tumolva, C., & Tomeldan, D. (2004). Domestic workers and caregivers' rights: The impact of changes to BC's employment standards regulation. *Canadian Woman Studies*, 23(3/4), 153-156.

Turner, L. (2007). Medical tourism: Family medicine and international health-related travel. *Canadian Family Physician, 53*(10), 1639-1641.

Unifor. (2019). Caring in Crisis: Ontario's Long-Term Care PSW Shortage Report & recommendations from the front lines across Ontario Commissioned from the Ontario Health Coalition by Unifor. Retrieved December 17th, 2019 from https://www.unifor.org/sites/default/files/documents/document/final_psw_report.pdf

Van Manen, M. (1990). *Researching lived experience: Human science of an action sensitive pedagogy.* London, ON: The Althouse Press.

Ward-Griffin C, Brown J, Vandervoort A, McNair S, Dashnay I. (2005). Double duty caregiving: Women in the health professions. *Can J Aging, 24*(4):379-394.

Ward-Griffin C, Martin-Matthews A, Keefe J, Kerr M, Brown JB, Oudshoorn A. (2009). Development and validation of the double-duty caregiving scale. *Can J Nurs Res., 41*(3):108-128.

Ward-Griffin, C., Brown, J., St-Amant, O., Sutherland, N., Martin-Matthews, A., Keefe, J., & Kerr, M. (2015). Nurses negotiating professional–familial care boundaries: Striving for balance within double duty caregiving. *Journal of Family Nursing, 21*(1), 57-85.

Waterloo/Wellington Community Care Access Center. (2011). Connecting you with the Waterloo/Wellington CCAC. Retrieved December 13th, 2019 from http://www.ontla.on.ca/library/repository/mon/25007/310977.pdf

Weingart, S. N., Pagovich, O., Sands, D. Z., Li, J. M., Aronson, M. D., Davis, R. B., . . . Phillips, R. S. (2005). What can hospitalized patients tell us about adverse events? learning from patient-reported incidents. *Journal of General Internal Medicine, 20*(9), 830-836.

Wendell, S. (1997). *The rejected body: Feminist philosophical reflections on disability.* New York, NY: Routledge.

Whiteside, H. (2009). Canada's Health Care "Crisis": Accumulation by dispossession and the neoliberal fix. *Studies in Political Economy, 84*(1), 79-100.

Whiteside, H. (2011). Unhealthy policy: The political economy of Canadian public private partnership hospitals. *Health Sociology Review*, 20, 258–268.

Wiles, J. (2011). Reflections on being a recipient of care: Vexing the concept of vulnerability. *Social & Cultural Geography, 12*(6), 573-588.

Williams A. P., Peckham A., Rudoler, D., Watkins J., & Tam T. (2013). Caregiver support project: Formative evaluation. Final report. Retrieved June 2nd, 2019 from https://alz.to/wp-content/uploads/2019/04/csp_evaluation_report_2013.pdf

Williams, A. (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine, 55*(1), 141-154.

Williams, A. M. (2006). Restructuring home care in the 1990s: Geographical differentiation in Ontario, Canada. *Health & Place*, *12,* 222– 238.

Williams, F. (2001). In and beyond new labour: Towards a new political ethics of care. *Critical Social Policy, 21*(4): 467–93.

Wong, S. & Regan, S. (2009). Patient perspectives on primary health care in rural communities: Effects of geography on access, continuity and efficiency. *Rural and Remote Health, 9,* 1142-1153.

Yakerson, A. (2019). Home care in Ontario: Perspectives on equity. *International Journal of Health Services*, *49*(2), 260–272.

Yu, M., Guerriere, D. N., & Coyte, P. C. (2015). Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada. *Health & Social Care in the Community, 23*(6), 605-618.

Zeytinoglu, I. U., Denton, M., Plenderleith, J., & Chowhan, J. (2015). Associations between workers' health, and non-standard hours and insecurity: the case of home care workers in Ontario, Canada. *International Journal of Human Resource Management*, *26*(19), 2503–2522.

Appendix A: Interview Guide

Has everything been explained to your satisfaction?

Are you ready to begin the interview? We can start at any place, wherever you feel most comfortable, and remember you do not have to answer all of these questions and you can stop the interview at any point in time.

- How old are you?
- Are you presently employed?
- What level of education have you completed?
- Of the following four ranges, what is your annual household income: less than $30,000, $30,000 to $50,000, $50,000 to $80,000, or over $80,000?
- Do you identify as a person with a disability?
- Is there any other personal information that you feel is relevant and would like to share in regards to basic information about yourself?
- Can you tell me how you prepared yourself for total joint replacement surgery (TJR)? For example: Did you research online? Did you speak with others that underwent TJR previously? Did you make any adaptations to your home to accommodate for changing mobility?
- What was your experience of diagnosis like?
- What kind of barriers have you faced in health care?
- What would you like to see improved, if anything, in the current system?
- How did your home space change as you recovered from surgery?

- What kinds of experiences did you have in hospital or in the community before and after TJR that stick out for you?
- What other issues are important to you?
- Is there anything further you would like to add?

Appendix B: Letter of Information/ Consent

DATE: October 6th, 2014

LETTER OF INFORMATION / CONSENT

A Study about how place matters to individuals waiting for, through to recovery from total joint replacement

Investigators:

Student Investigator:
Keri Cameron
School of Geography and Earth Sciences
McMaster University
Hamilton, Ontario, Canada
(519) 954-2489
E-mail: camerkl@mcmaster.ca

Faculty Supervisor:
Dr. Vera Chouinard
School of Geography and Earth Sciences
McMaster University
Hamilton, Ontario, Canada
905-525-9140 ext. 23518
E-mail: chouinar@mcmaster.ca

Purpose of the Study:
The objective of this research is to uncover how place matters[12] to individuals undergoing total joint replacement and increase experiential knowledge of this group of individuals. I am conducting this research for my doctoral thesis.

You are invited to take part in this study on spatial experiences of total joint replacement. I want to better understand how place impacts experiences of waiting for, through to recovery from total joint replacement. I am hoping to learn more about your experiences from your perspective as an individual that has undergone this surgery. I also hope to find out how and what about these community, health and home spaces affect your experiences in positive and adverse ways.

Procedures involved in the Research:
Information will be obtained through an interview between you and I at a time and place of your convenience between December 2012 and April 2015. You will be asked to take part in a one on one interview with Keri Cameron. This interview is expected to last between 30 and 120 minutes. The interview will focus on your experience of waiting for, through to recovery from surgery. I will ask you for some demographic/background information like your age and education. I will also ask you questions about your experience of waiting for surgery. Additionally, you will be asked to provide any information you are comfortable with and find relevant. You may choose where the interview takes place or the interview can take place over Skype. With your permission I will take handwritten notes and audio-tape the interview. (Please see attached interview guide).

Potential Harms, Risks or Discomforts:
By participating in this research study, you will experience no more than minimal risk. Your identity can be protected through using a fake name in place of your name. However, based on the information you provide, there can be a small risk that you may be recognized by others. The identity of your family and health care providers, and the hospital and the rehabilitation center you attend will be protected through the use of pseudonyms.

It is not likely that there will be any harms or discomforts from/associated with participating in this research, however there are potential emotional risks associated with reflecting on difficult experiences. For example, it may be difficult to share specific thoughts associated with the care you received during this experience or it may be difficult to share specific experiences. I will pause the interview if you do appear upset or anxious to ask how you are feeling and whether you want to continue. During interviews you have the option to discuss any or all aspects of your experiences before, during, and following total joint replacement surgery and have the right not to answer any questions you choose not to answer or you find uncomfortable. Your participation in this study is completely voluntary. You may withdraw from the study for any reason and without penalty, up until April 2015, when I expect to be submitting my dissertation.

Potential Benefits:
The research will not benefit you directly. There are no direct benefits to you in participating in this research study, however your participation contributes to our knowledge of disability geography and total joint replacement. Additionally, you will have opportunity to share your experience with the potential of these

experiences informing future research and informing others waiting for total joint replacement. It is your decision to choose what personal information of yours is shared in this research study and any future publication or presentation of findings.

I hope to learn more about your experiences. I hope that what is learned as a result of this study will help us to better understand how place impacts individuals' experiences of waiting for, through to recovery from total joint replacement. This could help physicians and surgeons prepare individuals for what they can expect throughout their journeys. This information will be provided to surgeons, physicians, and health-care professionals in Ontario in a short paper. The paper will not include any of your personal information and a pseudonym will be used in place of your name.

Confidentiality:

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. I will ensure that only my Faculty Supervisor and I as the Principal Investigator have access to transcripts of our interviews and notes taken during interviews by storing all files in a locked file cabinet in my residence. Information kept on a computer will be protected by a password. Once the study is complete, an archive of the data, without identifying information, will be maintained for ten years. Ten years after the study is complete, the data will be destroyed. Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. However, we are often identifiable through the stories we tell.

Participation and Withdrawal:

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to withdraw even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. You can withdraw from this study up until April 2015, when I expect to be submitting my dissertation.

Information about the Study Results

I expect to have this study completed by approximately April 2015*.* If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

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

E-mail: camerkl@mcmaster.ca
Phone: 519-954-2489

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the information letter about a study being conducted by Keri Cameron, of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time up until the submission of this dissertation.
- I have the right not to answer any particular question.
- I have been given a copy of this form.

- I agree to participate in the study.

Signature: ______________________________________

Name of Participant (Printed) ___________________________________

1. I agree that the interview can be audio recorded.

… Yes.

… No.

2. …Yes, I would like to receive a summary of the study's results.

Please send them to this email address

____

or to this mailing address:

____

____

____

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

3. I agree to be contacted about a follow-up interview and understand that I can always decline the request.

... Yes. Please contact me at:

____

... No.

Appendix C: Email Recruitment Script

McMaster
University

Inspiring Innovation and Discovery

Dear________,

My name is Keri Cameron and I am a PhD Candidate at McMaster University. I am conducting a qualitative study in the Waterloo/Wellington area and am looking for potential participants. I am looking for people who have been diagnosed with osteoarthritis and are waiting for hip or knee replacement in Ontario.

The objective of this study is to uncover how place matters to individuals that have undergone total hip and knee replacement and increase experiential knowledge of this group of individuals. I am conducting this research for my doctoral thesis. I want to better understand how place impacts experiences of waiting for, through to recovery from total joint replacement. I am hoping to learn more about experiences from the perspective of individuals waiting for surgery. I also hope to find out how and what about community, health and home spaces affect experiences in positive and adverse ways.

Individuals are invited to discuss their experience of hip and/or knee replacement. Interviews will follow a general guideline but will be open-ended in order to follow discussion topics as they arise during the interview. Participation would involve 1 to 2 sessions. Each session will be 30-120 minutes long, depending on the availability of the participant/s. Interviews will take place in a mutually agreed upon location. This may be in your home, at a local coffee shop, or over Skype. With the permission of participants, I will use a digital voice recorder to tape interviews.

All interviews will only be available to myself and my supervisor. Records and basic demographic information of participants will be used only for research purposes and will be kept in secure storage. I will use pseudonyms in all publications, and no one will be identified by name in this study.

This study has been reviewed and approved by the McMaster Research Ethics Board.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact the McMaster Research Ethics Board Secretariat.

Phone: (905) 525-9140 Ext.23142
Email: ethicsoffice@mcmaster.ca

Mail :
c/o Research Office for Administrative Development and Support
McMaster University
1280 Main St West
Hamilton, ON L8S 4L8

Appendix D: Recruitment Poster

PARTICIPANTS NEEDED FOR RESEARCH IN TOTAL JOINT REPLACEMENT

We are looking for volunteers to take part in a study of understanding how place matters to individuals waiting for, through to recovery from total joint replacement. We are looking for people who have been diagnosed with osteoarthritis and are waiting for total joint replacement in Ontario.

You would be asked to: take photographs throughout your experience and be interviewed about your photographs and experience. Interviews can take place in your home or at a local coffee shop of your choice.

Your participation would involve 2 sessions, each session will be 30-120 minutes long.

For more information about this study, or to volunteer for this study, please contact:

Keri Cameron

School of Geography and Earth Sciences

Phone Number:

Email: *camerkl@mcmaster.ca*

This study has been reviewed by, and received ethics clearance by the McMaster Research Ethics Board.