Medicalization of the Private Sphere: Home care services in Manitoba

by

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A Thesis Submitted to the Faculty of Graduate Studies of

The University of Manitoba

In partial fulfilment of the requirements of the degree of

DOCTOR OF PHILOSOPHY

Department of Sociology and Criminology

University of Manitoba

Winnipeg

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Abstract

Key words: Home care; medicalization; live-in caregivers; medical gaze; Foucault

While aging in place is often idealized as a way to maintain comfort, autonomy, and emotional connection, for many informal caregivers, the home becomes a medicalized space shaped by public home care services. Drawing on 13 semi-structured interviews and 6 home tours with live-in family/friend caregivers in Manitoba, this research explores how the integration of home care services into private residences affects caregivers' perception of home, autonomy, and social roles. Through a process known as medicalization, this research questions the extent to which home care delivery transforms private homes into institutional environments, and family/friend caregivers into medical providers. This research also investigates the extension of the medical gaze into the home, with caregivers increasingly participating in medical surveillance. Within this framework, it is evident that home care services not only impact the recipient of care, but also, through medicalization and medicalized technologies, transform family/friend caregivers and domestic spaces into objects and agents of the medical gaze. It reveals how home care embeds mechanisms of surveillance and discipline into everyday life, and ultimately reshapes notions of responsibility, care, and the home space.

Acknowledgements

I first want to acknowledge that this work was not completed without a village of support, and it is to them that I am eternally grateful.

First, thank you to Dr. Christopher J. Fries for your guidance and knowledge. It was in your grad class that I first connected medicalization with home care services, and for the first time, truly felt my sociological imagination developing. I would also like to thank my committee members, Dr. Laura Funk, Dr. Jeremy Patzer, Dr. Genevieve Thompson, and Dr. Cecilia Benoit. Your valuable insights, critical feedback, and suggestions helped to shape this work into what it is. I would also like to acknowledge that this research was supported by the Social Sciences and Humanities Research Council.

To my parents, Dave and Shawn. Never for a moment did you doubt my desire for a PhD or my eternal quest for knowledge. From a young age, you always encouraged me to do my best, to learn more, try more, and 'think outside the box'. It is your determined belief in me that I was able to push through the tough times. Although it may not have been easy, our experiences as a family together inspired this research. I hope that our challenges will one day inspire others, and ultimately make a change for other family/friend caregivers and recipients of home care.

To my husband, Riley. You have been my rock through this entire journey. You knew exactly when to bring me a snack, encourage me to take a nap, or tell me that it's time to get back to work. Thank you for being my partner in all that we take on together.

To my son, Tucker. Thank you for the reminders to take a step back from the research and see all the joy and goodness in the world.

To my extended friends and family. Your words of encouragement carried me through this experience. Although it was often said in jest, referring to me as 'Doctor' or 'the smart one' really did push me to one day become those things.

To the caregivers. This research would not be possible without you. I am forever grateful for your openness, honesty, and willingness to share your stories with me.

To Erin Scott. You pushed, pulled, carried, dragged, and helped me to the finish line. Get ready, you're next.

Dedication

To the caregivers.

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Chapter 1: Introduction

I recently went on a cruise with my family to celebrate my cousin's wedding. We spent two days in sunny Orlando, eight nights on a ship with a balcony overlooking the vast blue ocean, had an unlimited drink package, and witnessed a beautiful ceremony by the beach on a private island. Everything sounds idyllic, and for many on the trip, it was a truly relaxing vacation with time to unwind and celebrate a joyous occasion for loved ones. For my Dad and myself, however, this experience was more complex. Our travel companions included my toddler, my mom, and my grandfather. My mom and grandfather both are recipients of home care from Manitoba's home care program, and receive services to assist with personal care, dressing, meal preparation, light housekeeping, and medication assistance. While we were on this vacation, my Dad and I became full-time caregivers, performing the roles of home care workers, and helping with the tasks needed to ensure my mom and grandfather could enjoy their trip. In our suitcases, carry-ons, and beach bags were a variety of medical supplies. My mom uses a power wheelchair and a white cane, and my grandfather uses a walker. Toddler in tow, the phrase 'you've sure got your hands full!' from total strangers made it clear we were quite the spectacle everywhere we went.

For my Dad and myself, this was not an unusual experience. We have both been live-in caregivers for nearly 20 years and have long ago integrated the functional aspects of caring into our roles as family members. Although I have not been a live-in caregiver for several years, the experience on the cruise reminded me just how simultaneously tiring and rewarding that experience can be. It is for my Dad and myself, that I wanted to learn more about family/friend caregivers and the homes where care is provided.

For many people, home is a place of comfort and normality (Boccagni & Kusenbach, 2020). Home is where you can be yourself and surround yourself with your favourite people and possessions. It is a place where connections are made and traditions established. As a concept, "home is both an emotion and a place imbued with meaning generated through the everyday life routines enacted in it, the sense of protection and intimacy it emanates and the largely positive memories of the past (and possibly future aspirations) it may elicit" (Boccagni & Kusenbach, 2020, p. 597). Memories of home are often accompanied by the smells, sights, and sounds that helped to shape us into the people we have become (Mong, 2020). Our homes can be messy from the chaos of hosting a family dinner or bear the marks of walls dented from where a child threw a baseball through a window. Homes are where families come together to celebrate birthday and graduation parties or share in each others' sadness to mourn.

When I think of my childhood home, I think of sitting on the kitchen counter while singing and baking cookies with my Mom. I think of my Dad hosting huge Christmas Eve parties that were open to family, friends, and neighbours that lasted into the early hours of the morning. But when I look around that home, I also see a curtain instead of a bathroom door. I see a bench in the shower and grab bars on the walls. I see a loading zone and wheelchair ramp outside the house, and a pantry filled with Thicken Up[1]. I remember running home after a hard day at school to seek comfort from my Mom, however, she was with a respite worker, and I had to hold in my emotions and engage in small talk with the worker instead.

My journey as a live-in family caregiver began in 2007 when I was in middle school. In addition to facing the struggles that the teenage years bring like homework, extracurriculars, and

[1] Tasteless, odourless powder that thickens liquids for individuals with swallowing issues. https://www.nestlehealthscience.ca/en/brands/resource-thickenup/thickenup-clear

friendships, I was also learning how to properly dress a tracheotomy, blend food to the correct consistency so it could be swallowed without choking, and do laundry. While I am no longer a live-in caregiver, I continue to provide care and this experience influences who I am today. And while I am grateful for the home care services that allowed my Mom to live at home all these years, when reflecting back, I cannot ignore the sociological processes I was observing as they manifested in my home environment. My experiences as a family caregiver motivate my sociological interest in a process known by sociologists as 'medicalization' (Conrad, 2009) within the public home care system here in my province. I recognize that I was not alone in this experience; that other caregivers may have similar stories to mine. Using my sociological imagination to understand my personal troubles as social issues (Mills, 1959), I seek with my research to better understand how other family caregivers in Manitoba experience their families' receipt of and interactions with home care services, and how these experiences thereby impact their sense of home; I am also interested in how these experiences are connected with broader, sociological processes of medicalization.

It is a well-known fact that people are living longer than ever and nearly 20% of the Canadian population is over the age of 65 (Statistics Canada, 2024). As the Baby Boomer generation ages and their reliance on health and social care supports potentially increases, it is important to ask, where is the most desirable place for an individual to age? Beginning in the 1990s (Ceci & Purkis, 2011) there has been a movement towards deinstitutionalization (Rabig, Kane & Cutler, 2008), whereby individuals are encouraged to age at home, instead of in an institution such as a hospital or nursing home (Tamm, 1999), purportedly because a "person feels best in a natural environment" (Tamm, 1999, p. 49). In the name of cost saving, hospitals encourage patients with alternative levels of care to recover from home earlier than before (Allan

et al., 2021). Governments tell us that individuals who age at home will maintain their social integration, dignity, and independence (Province of Manitoba, 2017). However, is it possible to maintain independence when you are constantly being observed? Although the discourse of aging at home, with the help of medical professionals, such as home care services, celebrates independence and autonomy, it increasingly also serves a second purpose described by medical sociologists as medical surveillance (Armstrong, 1995). As I will demonstrate in my research, homecare, a service that is offered to (or can be purchased by) individuals with health and functional deficits (or their families), can in various ways be understood as a form of medicalization, which has brought the medical model of the public sphere into the private sphere of the home.

Do live-in informal caregivers, those who are living in the home but not directly receiving care, experience their private spaces differently, when opening their homes to home care services and workers? In asking this question, this research sociologically scrutinizes the seemingly intuitive concept of home care. Although widely promoted by government and private service agencies as allowing individuals with health, cognitive, or functional deficits to age with dignity in their own home, my personal experiences with home care have led to my sociological interest in these services that goes beyond the policy and program descriptions of the service. During my studies as a graduate student, as well as being a live-in caregiver to a home care recipient, I began noticing similarities between how homecare was delivered and organized and the processes described by health sociologists as medicalization (Busfield, 2017; Conrad, 2007; Nye, 2003). The current rationale of home care services is three-fold: (1) maintain the health of aging individuals by preventing early admission into long-term care facilities, (2) provide an alternative to long-term care facilities, and (3) provide a substitution for acute care that does not

require hospitalization (Sullivan & Baranek, 2000). Less formalized, although just as important, the reliance on home care programs in opposition to institutions, promotes the rhetoric that family matters should be private matters and that state services should be considered as a last resort (Montgomery, 1999). Thus, the discursive construction (Foucault; 1978) of "homecare" serves to institutionalize the cultural norm by which the family has a filial obligation to care for its aging members, aligning with the current neoliberal model of health care (Fierlbeck, 2011).

To the extent that they are closely aligned with and organized within regional health authorities and nursing services across Canada, publicly funded home care programs also allow the health care system to expand its reach beyond biomedical hospital care, to include multiple aspects of a person's daily function (Chappell & Penning, 2005; Heaton, 1999), such as assistance with Instrumental Activities of Daily Living (IADLs) (shopping, cooking, laundry, household maintenance, finances) and Activities of Daily Living (ADLs) (bathing, dressing, toileting). In order to assess and track needs, identify risks and allocate public services, these types of activities are both informally and formally monitored and reported upon by home care providers and associated health professionals, and in doing so, extend the boundaries of the medical gaze. Although this may be seen through the lens of "prevention", it can also turn relatively healthy recipients of home care into "pre-patients" (Rose, 2007) in need of constant monitoring and surveillance.

While the lives of home care recipients are becoming ever more visible, this trend continues to extend beyond them and surveil their informal/family caregivers. The term 'informal caregivers', or 'carers' is used in policy to describe any family or friend who aids in the care of an individual at home. Reducing costs to formal care systems, the approximately 6.8 million informal caregivers are estimated to provide the equivalent of $97.1-112.7 billion

annually, and 5.7 billion hours of care work (Fast et al., 2024). Their care work comes in many forms, including help with instrumental activities of daily living and activities of daily living, management of formal care services, and providing emotional and social support (Fast et al., 2024). Counterintuitively, the way that public homecare tends to be organized and delivered in many Canadian regions, including but not limited to Manitoba, may require recipients and their families to reconfigure their personal space, schedules, concepts of privacy, and social roles in relation to the care recipient. My sociological interest lies in how live-in caregivers are affected by the provision of home care services to their family members.

In a neoliberal context (Ayo, 2012; Schrecker & Bambra, 2015; Dalmer, 2019), home care is promoted by the health care system as an alternative to institutional care, which maintains autonomy, independence, and dignity. In a neoliberal cultural climate where individualism is valued, aging at home for as long as possible is perceived as 'the right thing to do' (Davidson, 2015; Dalmer, 2019; Rubinstein & de Medeiros, 2015). By promoting that the home is the best place to age, individuals normalize the idea of being 'in charge' of their care, while 'under the supervision' of the homecare providers, thus willingly opening their homes to the medical model. In this regard, home care may be understood sociologically as a form of surveillance medicine (Armstrong, 1995). Treating the home like a hospital, and the family as medical attendants can erode the ontological security afforded by 'home'. Furthermore, extending the clinical gaze to private spaces grants the institution of medicine significant power in defining social reality and regulating deviance and social disorder within the private sphere.

Existing scholarship has examined the relationship between home care services, workers and informal caregivers and is dominated by calls to include informal caregivers in the caring process (Arras & Dubler, 1994; Buscher, Astedt-Kurki, Paavilainen, & Schnepp, 2011; Chappell

& Penning, 2005; Lindahl, Liden, & Lindblad, 2010; Keefe, 2011; Montgomery, 1999; Silver & Wellman, 2002; Wiles, 2003). Much of this research is focused on providing ways for informal caregivers to continue in their caregiving roles, as our current home care system would not be possible without them (Chappell, 2011). More recently, scholarship on informal caregivers has highlighted the ways in which some informal caregivers might not 'fit the mould' of traditional caregivers (always available and willing to provide support) (Funk et al., 2024; Davidson, 2015). There is some research focused on the private home space itself (Dyck et al. 2005; Tamm 1999), and how this space may be affected by becoming a medical workplace (England & Dyck, 2011), and although research has discussed how informal caregivers perceive their roles, it is limited in its scope in terms of medicalization. The present research fills this gap by answering the following research questions:

> *(1) how regulated spaces of medical centres, such as hospitals and personal care centres, extend their care to function in a private home setting;*
>
> *(2) how private spaces are adapted to fit the rigid and regulated medical model of the public space, and;*
>
> *(3) how do informal caregivers adapt to, participate in, and interpret changes in their home and social role?*

Informed by Foucauldian concepts of medical gaze, biopower, medical surveillance, and governmentality (Foucault, 1975, 1987, 2008), this study further critically interrogates the consequences of the contemporary delivery of public home care for live-in caregivers and their homes. More broadly, this research will investigate flows of power from a Foucauldian

theorization, including regulation, normalization, and control according to a regime of practices within neoliberal times.

1.1 Outline

This dissertation is organized into six chapters, each building on the next to provide a comprehensive analysis of the medicalization of home, and the experiences of live-in family/friend caregivers in Manitoba. Chapter 2 provides a comprehensive literature review of existing research as well as providing an introduction to the development and current state of home care services in Manitoba. The literature review will discuss the evolving role of family caregivers, and identify how, when, and why they are discussed in policies such as *The Caregiver Recognition Act,* and more generally by the larger society. Chapter 2 concludes with a review of the ways in which homes are modified to allow for home care services to function, and the medical and other tasks family/friend caregivers are often expected to provide.

Chapter 3 presents the theoretical framework that guides this research, focusing on Foucauldian concepts of the "medical gaze" (Foucault, 1975), "surveillance medicine" (Foucault, 1963; Armstrong, 1995), and "biopower" (Foucault, 1978). These are but elements in a larger project inspired by Foucault, described as "regimes of practice" (Dean, 1999) by which particular, governable subjectivities are discursively produced at a variety of institutional sites. This chapter moves through a discussion of Foucault's concept of biopower, which proceeds through the internalization of medical discourse, and the expansion of medical authority beyond the individual to their surrounding environment.

Next, chapter 4 details the research methodology and the approach used to collect and analyze the data. Chapter 4 pays special attention to the impact of autoethnography and how I

was able to use my dual position as a caregiver and as a researcher to gather rich narratives from the participants.

Chapter 5 presents the findings of this study which are thematically organized into sections based on the key aspects of the caregiving experience. The themes are: what 'family' means to family/friend caregivers; what 'home' means to family/friend caregivers; modifying home; medical tasks and technologies; medical errors; identity and relationship changes; and decision-making and trust. Chapter 5 also presents photographs taken in some of the caregivers homes that show elements of medicalization.

Chapter 6 will synthesize the findings within the theoretical framework of medicalization and surveillance medicine. It examines the implications of biopower in home care, the agency of caregivers in decision-making, and the broader impact of medical technologies in the home. This chapter will also reflect on the limitations of the study and offer suggestions for future research. Chapter 6 make suggestions about how to include family/friend caregivers in the home care process and discusses the impact of medicalizing homes and family/friend caregivers through the home care program, and makes suggestions for future research.

Chapter 2: Literature Review

2.1 A Brief History of Home Care in Manitoba

The idea of a publicly funded homecare program initially gained popularity in the 1970s after the White Paper[2] on Health Policy promoted the notion of 'aging in place' (The Manitoba Medical Association, 1973). The Manitoba Medical Association (1973) found that health care costs were rising unsustainably and that access for all Manitobans was inequitable. While it is true that the initial vision and goals of home care in Manitoba were influenced by social gerontologists and grounded in models of health promotion, the justification and implementation of home care have shifted significantly over time (Ceci & Purkis, 2011). Originally framed around ideals such as supporting independence, improving quality of life, and preventing health decline, these goals have remained vaguely defined and increasingly difficult to uphold amid changing policy priorities (Ceci & Purkis, 2011). Since the 1990s, home care has been recast more as a mechanism of institutional diversion in response to an aging population perceived to pose an unsustainable burden on the health system (Montgomery, 1999; Ceci & Purkis, 2011). This shift coincided with growing fiscal pressures and technological advances that enabled more sophisticated medical interventions in the home, but also enabled a redefinition of care priorities, often favouring those deemed 'medically necessary' over those with low-level or supportive care needs (Ceci & Purkis, 2011).

In the 2004 Accord, *A 10-year Plan to Strengthen Health Care,* Canada committed to improving home care services and providing first-dollar coverage for certain services, including

[2] White Papers are government reports that outline current problems and solutions to help align government priorities.

mental health services, acute care, and palliative care services by 2006 (Government of Canada, 2004). This was in response to the Romanow Commission (2002), which highlighted the importance of home care to Canada's health care system However, home care services are not in the *Canada Health Act*, and thus, are under provincial jurisdiction. Because of this, there are no national standards for home care programs and access, with comprehensiveness varying widely from province to province (Sullivan & Baranek, 2000; Statistics Canada, 2022). In 2018, improving access to home and community care is one of two[3] priority areas agreed upon by the *Common Statement of Principles on Shared Health Priorities,* endorsing all governments to work together to respond to the ever-changing needs of Canadians (Government of Canada, 2018a).

Within Manitoba, home care services vary widely, as organization and funding are determined by one of Manitoba's five regional health authorities (Toews, 2016). Homecare services were first universally provided at no cost in 1974 by the Province of Manitoba (Roos & Havens, 1991). Manitoba was, interestingly, also the first province to introduce legislation formally recognizing informal caregivers, many years later (Government of Manitoba, 2018), known as the *Caregiver Recognition Act.* According to the Canadian Institute for Health Information (CIHI), "the most established and comprehensive universal homecare program in Canada is the Manitoba Home Care Program" (Keefe, 2011, p. 15), thus making Manitoba an important province to research the home care system.

Home care in Manitoba is a community (i.e., non-institutional) service where medical professionals, nursing and/or allied health professionals, and trained support staff enter the home

[3] Improving access to mental health and addictions services is the other identified priority.

to assist in caring for individuals with health and functional deficits, to help them safely stay in their homes for as long as possible (Government of Manitoba, 2018c). The services provided by homecare can include nursing care, personal care, home support, and respite services (Forbes & Edge, 2009; Government of Manitoba, 2018b). The stated objectives of the home care program in Manitoba are to promote autonomy, independence, and self-determination for the individual receiving care (Government of Manitoba, 2018c). According to the Government of Manitoba (2018) "regional health authorities (RHAs) provide home care services to eligible individuals, regardless of age, who require health services or assistance with activities of daily living. Home care works with individuals and provides assistance to help them stay in their homes for as long as is safely possible".

Home care involves a wide range of tasks which can include everything from respite for informal caregiver(s) to preparing meals (usually only a 'heat and serve'), helping with care tasks such as dressing and washing, laundry and housekeeping (though in Manitoba, this is now rarely available) and in some cases to major medical tasks including providing medications such as pills or injections, changing catheters and ostomy bags, and monitoring blood pressure and blood sugar levels, managing peritoneal dialysis, and providing nutrition infusions (Silver & Wellman, 2002; Mong, 2020). With the rise of new technologies and depending on the person's health needs, medical equipment such as: hospital beds; dialysis machines; Hoyer lifts; and oxygen tanks can also often be brought into the home as part of the home care plan (Arras & Dubler, 1994; Mong, 2020). Due to cost constraints in recent years alongside trends towards earlier hospital discharges and for aging populations to remain at home for longer, home care services have become more narrowly focused on providing the most essential and medical supports, and far less social and emotional care to recipients (Chappell & Penning, 2005).

Medical tasks in particular are prioritized, while social supports (as well as laundry/light housekeeping) are often the first to be cut when there are staffing shortages, which was magnified particularly during the COVID-19 pandemic (Funk, et al., 2021). Further, tasks that were once the responsibility of trained nurses such as wound care and catheter and ostomy management are now being delegated to homecare aides or family members under nursing supervision (McDonald et al., 2016 Mong, 2020), for the purpose of cost-containment, as well as to manage scheduling and staff retention problems (Toews, 2016).

Although publicly funded and delivered home care services are potentially available to all individuals who need help with aspects of daily living, they are not provided until existing supports and resources have been considered and/or exhausted (Government of Manitoba, 2018c). The result is that home care services are often not provided proactively and are usually only introduced after a crisis or emergent health incident (Stall, 2019). Although home care services are assessed to match the needs of the recipient of care, they are structured around the availability, willingness, and assessed abilities of their family (Montgomery, 1999; Funk et al., 2024). For instance, it is expected that family caregivers will do as much as they can and home care will 'fill the gaps' (Toews, 2016). It is important to note that home care services are not 'guaranteed,' thus when formal care is not available, family, friends or neighbours are required to function as a stable 'backup' plan. Manitoba is the only province that has a policy indicating that all care recipients must have a backup plan in place (Toews, 2016). Notably, backup plans are utilized quite often by care recipients, an average of 3.7 times in the span of three months, due to frequent visit cancellations in this province (Toews, 2016). Manitoba's current home care system is designed with the formal and informal providers as substitutes for one another (Funk,

2012; Funk et al., 2024), not necessarily as complementary resources that offer collaborative support.

Although persons receiving home care are most commonly referred to as ‘clients,’ my research will not use this term. ‘Client’ is often associated with a business transaction, whereas ‘person’ implies humanity (Wolff & Boyd, 2015). This is an important distinction for those providing and researching health care services. Internationally, and within Canada, there has been a shift from system to person-centred care. While system-centered care follows strict bureaucratic procedures, person-centred care (PCC) and family-centred care (FCC) have been described as “the pinnacle of health care quality” (Wolff & Boyd, 2015). This extension has even been legislated, for example, “the WHO has pointed out the nurses’ responsibility for the health of the whole family when one family member gets a disease” (Fjelltun, Henriksen, Norberg, Gilje, & Normann, 2009, p. 25). Beginning in primary care, the language and principles of person-centred care are slowly being adopted in older adult care across the care continuum, (Coulourides Kogan, Wilber, & Mosqueda, 2015), including in the community, in assisted living, and long-term care facilities. Person-centred care is a holistic approach that means putting the needs of the person receiving care first. Person-centred care and terminology strive to dismantle the medical hierarchy that currently has medical professionals on the top, and receivers of care on the bottom (Koren, 2010). Thus, using ‘recipient of care’ or ‘care recipient’, as is used in this research, is more neutral terminology and will be used in this research. Given the reliance on informal support networks, the following section will examine the role of family/friends caregivers within the broader home care system.

2.2 The Role of Family Caregivers

As noted above, informal caregivers are viewed as essential by the home care program. There is a breadth of research considering how caregivers 'fill in the gaps' of home care, or provide care 'alongside' formal care systems (Funk, 2012; Funk et al., 2024). Regardless of the nature of care, informal caregivers are central to home care, and thus must be included in research. In recent years, informal caregivers have also provided support with advanced medical technologies as many of these treatments no longer must be provided exclusively in hospitals (McDonald et al., 2016; Stall, 2019). However, the increased technological sophistication of some caregiving tasks "requires knowledge and skills in processes that resemble professional clinical skills", that informal caregivers may not be properly trained in or comfortable providing (Silver & Wellman, 2002, p. 834).

There is also a gendered component to caregiving. Women are more likely to be caregivers than men (Chappell, 2011; Keefe, 2011), whether as spouses, children, in-laws, friends, or neighbours. They are also more likely to provide more intensive forms of care including personal care, whereas men are more likely to perform more discretionary tasks and help with IADLs (Fast et al., 2024). Historically, the distinction between private and public spaces has changed, however, domestic care tasks are often undertaken 'invisibly' by women in the private space, as they are socialized to engage in this type of care work (Armstrong, 2005). Women are often "conscripted" (Armstrong, Armstrong, & Coburn, 2001, p. 168) into providing care in the home and may not fully know the toll it will take on their lives until they have reached a crisis point (The Change Foundation, 2019).

Informal caregivers have been shown to experience both positive and negative feelings about and outcomes related to caring, sometimes even simultaneously. Negatively, informal caregivers are more likely to experience feelings of depression, guilt, loneliness, and anxiety compared to non-caregivers (Chappell, 2011; Bedini, Gladwell, Dudley, & Clancy, 2011; Davidson, 2015; Roth, Fredman, & Haley, 2015; Cross, Garip, & Sheffield, 2018; Hango 2020). Many informal caregivers experience chronic stress about the caregiver situation and have shown reduced ability to cope with their stress (Davidson, 2015; Roth, Fredman, & Haley, 2015; Cross, Garip, & Sheffield, 2018; Vanier Institute, 2017). Being an informal caregiver can mean abandoning or reducing leisure time, which can lead to social isolation (Cross, Garip, & Sheffield, 2018; Stall 2019; Hango, 2020). The Canadian Institute for Health Information (2010) finds that one in six caregivers experiences distress, with those caring for a senior with cognitive impairment being more at risk. In addition, those who live with the care recipient, such as spouses and adult children, are more likely to provide more intensive care for longer periods of time (Canadian Institute of Health Information, 2010), and are more likely to experience caregiver burnout. From 2002-2015, the prevalence of caregiver distress for carers who live with the care recipient grew steadily from 22%-26% (Toews, 2016). During the Covid-19 pandemic, 60 percent of caregivers in one Manitoba study (albeit a convenience sample) reported providing more care than they were before the pandemic, and 57 percent and 52 percent of caregivers reported a decline in mental and physical health, respectively (Funk, Penner, Dansereau & Kuryk, 2021).

Further, informal carers are more likely to take time off work and to forgo employment advancement than non-caregiving counterparts (Chappell & Penning, 2005; Cross, Garip, & Sheffield, 2018; Government of Canada 2015). This can exacerbate financial burdens, as

informal caregivers may pay out-of-pocket expenses, such as travel costs, groceries, and medical costs (Government of Canada,, 2015; RANQ, 2020). Loss of work can have a particularly negative effect on low-income workers, as they are less able to negotiate time off to care for aging adults (Government of Canada, 2015; Cross, Garip, & Sheffield, 2018). A study conducted in Quebec found that nearly 57 percent of caregivers (from a convenience sample) feel they lack the financial resources to help the person they cared for during the Covid-19 pandemic (RANQ, 2020).

Positively, some informal caregivers can experience feelings of self-affirmation, enjoyment, and a sense of satisfaction (Chappell, 2011; Cross, Garip, & Sheffield, 2018; Hango 2020) from the caregiving experience. Children who are caregivers may feel they are returning the caregiving that they received from their parents (Chappell, 2011). Caregivers may also feel that they are simply caring for their loved ones because that is what families are supposed to do (Guberman, Lavoie, Blein, & Olazabal, 2012; Hango 2020). For those caring for someone with chronic and/or terminal illnesses, some caregivers feel that despite not being able to 'cure' the condition, providing care allows them to "do something" to help their loved one (Seaman, 2018, p. 67).

In addition, different relationships with the person receiving care may also impact the experience of caregiving. For example, a caregiving spouse may provide more intensive care for longer periods (Canadian Institute for Health Information, 2010; Keating, 2022; Fast et al., 2024) while caregiving children may spend more focused caregiving time because they may not live with their parent who is receiving care (Penrod, Kane, Kane, & Finch, 1995; Stall, 2019). It is also important to acknowledge that less is known about 'new' family forms, (i.e. those who are

childless, divorced, cohabitating) and changing fertility norms, which could have an impact on who is expected to provide care, and how much (Keating, 2022).

Although informal caregiving is promoted in Western culture as a 'choice' (Montgomery, 1999), or moral filial responsibility, in reality, many families have no other options (Chappell, 2011; Stall, 2019). Strained family relationships, work responsibilities, and personal health can all impact a caregiver's availability and willingness to provide care (Funk, 2012). Regardless, caregivers may feel pressured or strongly encouraged to provide care by general practitioners or other medical professionals, whether or not they are able or willing (Wiles, 2003; Toews, 2016). Funk (2013) finds that caregivers who are resistant to caring responsibilities were described by health care professionals as "need[ing] to be negotiated and managed, for example, by explaining limitations of formal services" (p.93) potentially coercing them into caregiving roles. It is important to remember that "family ties do not automatically translate to knowledge about caregiving" (Montgomery, 1999, p. 406), however, it can be difficult to separate labour from love (Armstrong, 2005) which can further complicate the public/private care dichotomy. As explained by Armstrong (2005), "[i]n the private sphere, there is often little distinction for women between work and non-work time or space, and their control over their labour may be more apparent than real" (p. 174).

Unpaid work is often viewed as less valuable or easier than paid work (Armstrong, 2005). In particular, the 'caring' work of informal caregivers is often contrasted with the 'curing' work of medical professionals (Seaman, 2018), which can minimize the impact and importance of family/friend caregivers. Much of the work done by caregivers also "involves household and relational labor that can look and feel remarkably similar to daily life" (Seaman, 2018, p.69) and thus can often be dismissed with 'normalcy' (Seaman, 2018). As a result, informal caregivers are

somewhat hidden, thus they can be a difficult population to address and support. However, it is important not to dichotomize 'care' and 'cure' mentalities, which can further marginalize and normalize the work that caregivers do (Seaman, 2018).

Complicating things further, many caregivers do not identify themselves as 'carers' (Wiles, 2003), whether for cultural reasons, as a form of resistance to the role, because they are in a cycle of 'serial caregiving[4]' or simply because may be hard to differentiate the tasks they perform from the everyday tasks of maintaining a household (Health Council of Canada, 2012; Penrod, Kane, Kane, & Finch, 1995; Hoefman, van Exel, & Brouwer, 2013; Stall 2019). Furthermore, caregivers may "assume their caregiving identity as one among many social identities and refuse to define themselves only through their role as a caregiver" (Guberman, Lavoie, Blein, & Olazabal, 2012, p. 214).

Caregivers are also difficult to define because they are often not defined as caregivers until they have had some involvement with the formal system (Heaton, 1999; Seaman, 2018). For example, respite services can only be offered to caregivers if they are already receiving formal care (Stall, 2019; The Change Foundation, 2019). This can be difficult for many caregivers to manage; they may not feel a part of the care network, because they are providing care 'invisibly' in the home (Wiles, 2003; The Change Foundation, 2019). Caregivers may not feel they have legitimate negotiating power with formal care providers and may not be able to see the full care network as a whole when they are looking at it from the in-home perspective (Wiles, 2003). Caregivers may also not want to identify as such, because admitting to needing formal support often occurs during times of crisis, thus forcing the caregiver to admit 'failure'

[4] This is a process whereby caring becomes normalized (Hill, 2009), as individuals care for their children, aging parents, and spouses in succession (Chappell, 2011; Stall, 2019).

(Wiles, 2003; Stall, 2019). Because they are so close to the caregiving situation, it can be hard for caregivers to recognize when they need help before it is too late. Thus, the invisible and forgotten nature of care work means that caregivers are often absent in policies, society, and research. This research brings informal caregivers to the forefront.

2.3 Recognizing Family/Friend Caregivers

The Foucauldian subject position of 'carer' is discursively created by informal care policy (Heaton, 1999), or in other words, caregivers did not exist as such until they were included in policies. Dialectically, as homecare programs continue to be relied upon and the need for informal caregiving grows, numerous scholars and caregiver support organizations have advocated for the need to formally acknowledge the importance of informal caregivers *through* policy. It has also been noted that Canada significantly lags behind its European counterparts in providing support for caregivers (Keefe, 2011). As noted by Chappell (2011),

> "policies that support the needs of caregivers are important for several reasons: the formal care system could never replace all of the support provided informally, caregivers express a desire to continue in this role, and many caregivers make great sacrifices in order to provide the care that they do (p.14).

If the assumption continues to be that family members are, or should be, available to provide care at no cost to the state, and to the detriment of their health and employment, then they should be supported and legally recognized in their endeavours. In a study on caregivers in Canada, Keefe (2011) states:

> "a range of policies to support the participation of family and friend caregivers in caring for older Canadians must be considered. The policy domains span labour, income security, home and continuing care, health promotion and education and training. The purpose of policies is to support caregiving activities and mitigate negative outcomes associated with caring for older persons. For example, labour policies need to be designed to enable caregivers to maintain

> some attachment to the labour force and to reduce the negative consequences of job interruption, reduced income and lower retirement pensions" (p.28)

In the same study, Keefe also notes that a National Home Care strategy would be ideal, with national guidelines, standards, and repercussions if benchmarks are not met. However, provincial home care policies and jurisdictional debates will likely prevent something like this from occurring (Di Matteo & Emery, 2015). Keefe (2011) states that until a National Homecare strategy is put in place, "concrete policies are needed to support family caregivers and enhance the homecare system to meet the needs of the aging population" (p.29).

One of the challenges facing caregiver policy implementation is the individualized nature of home care. Each older adult, family, and home are unique in their caregiving situation. Existing research argues that policymakers need to consider home care and caregiver policies that are flexible and interactive (Buscher, Astedt-Kurki, Paavilainen, & Schnepp, 2011). Health status can, and often will, change, and family relationships and the support they are able to provide will change along with it. Thus, it is suggested that policy needs to be dynamic and recognize that the best care for each case must be negotiated with the formal and informal caregivers respected as equal knowledge holders (Buscher, Astedt-Kurki, Paavilainen, & Schnepp, 2011; Wiles, 2003; Chappell, 2011; Funk et al., 2024).

Currently, in Manitoba, there is no standardized process for assessing the availability of informal care resources. It was found by the Manitoba Auditor General in 2015 that,

> "Determining the availability of family resources was challenging. The policy required case coordinators to consider 'those activities which others in the household, or which family/friends living within a reasonable distance, are performing, or realistically could perform'. However, regional home care staff said that often determining this was a matter of negotiation, not assessment. Negotiation can lead to inconsistent and therefore unequal treatment. Some family members may agree to provide more support than others and some case coordinators may be more assertive than others…Neither

> region gave its case coordinators any specific training on negotiation" (Ricard, 2015, p. 21).

Thus, it was recommended in the Auditor General report that standardized measures be put in place to fairly assess the availability of informal support systems (Ricard, 2015). Interestingly, Manitoba is the only province in Canada that has a policy requiring home care recipients to have a backup plan (Ricard, 2015).

Although recognizing caregivers in policies may be a good thing for highlighting the need for caregiver support, it may have a latent effect of embedding the informal caregiver into the caring process (Funk et al., 2024), thus reinforcing a neoliberal ethic of care.

2.3.a THE CAREGIVER RECOGNITION ACT

The *Caregiver Recognition Act* (Bill 42) was spearheaded by the Minister of Healthy Living, Seniors and Consumer Affairs, the Honourable Jim Rondeau. It was the first of its kind in Canada to formally recognize the essential role played by informal caregivers (Funk, 2012). The Bill was supported by the then ruling NDP party, the Manitoba General Employees Union (who represent home care workers), the Manitoba Caregiver Coalition, and the Canadian Caregivers Coalition (Funk, 2018). It was modelled after a similar bill that was passed in Australia in 2010[5] (Kohler, 2018). The expansion of home care was a top priority, and the need to support informal caregivers to maintain the expansion of home care was recognized (Funk, 2018a). In the process of conducting the *Future of Home Care Report*, it was noted that "replacing the service provided by family and informal caregivers with home care service was

[5] The Australian *Carer Recognition Act* dictates 10 Principles for Carers which are very similar to those outlined in the *Caregiver Recognition Act.* Although the *Carer Recognition Act* does not suggest a tax credit or appoint a 'Caregiver Recognition Day', it does require that each home care agency reflect upon the Principles of the Act, take practical measures to implement and evaluate supports to carers, and report annually on compliance (Australian Government, 2010)

quickly set aside with the realization that 80% of home care services are provided by family and informal caregivers" (Toews, 2016). It was recognized by researchers that supporting informal caregivers would reduce some of the economic burdens on the formal care system in the long term (Toews, 2016; Funk, 2018). It was also suggested that Manitoba wanted to be the first with caregiver legislation, to maintain its status as the most established homecare program in Canada (Funk, 2018).

The *Caregiver Recognition Act* was designed to achieve three goals: "to increase awareness and recognition of caregivers, to acknowledge the valuable contribution they make to society, and to help guide the development of a framework for caregiver recognition and caregiver supports" (Bill 42: *The Caregiver Recognition Act,* 2011). Caregivers, in the Act, are defined as "a person who provides informal and unpaid care, support or assistance to another person because that other person lives with challenges due to a disability, an illness, an injury, or aging" (Bill 42: *The Caregiver Recognition Act,* 2011). The Act legislated that a Caregiver Advisory Committee be developed to provide the Minister with advice and recommendations on caregivers and their needs, improving caregiver awareness, and policies and services that relate to caregiving supports (Bill 42: *The Caregiver Recognition Act,* 2011). In addition, the Act also stated that a report be conducted every two years to review progress pertaining to the Act, describe caregiver needs, and develop an inventory of supports for caregiving Manitobans (Bill 42: *The Caregiver Recognition Act,* 2011), however, this was only done twice.

In addition to language about recognizing caregivers, there were also tangible outcomes legislated by the Act. Bill 42 proclaimed that the first Tuesday in April each year be known as Caregiver Recognition Day, and was intended to shine an appreciative light on the work done by caregivers (Bill 42: *The Caregiver Recognition Act,* 2011). This was later replicated by the

Federal government and declared National Caregiver Recognition Day in 2017 (Carers Canada, 2017). In addition, the Act also called for an increase in the Caregiver Tax Credit (Bill 42: *The Caregiver Recognition Act,* 2011), allowing carers to receive up to $1250 per person, per year, for up to three people. There are eight general principles relating to improving the lives of caregivers (Bill 42: *The Caregiver Recognition Act,* 2011). These include recognizing and respecting caregivers, acknowledging their unique experiences, allowing them to live an optimal life beyond their caregiving role, and providing them with economic supports (Bill 42: *The Caregiver Recognition Act,* 2011).

As a family caregiver working with the home care system since 2007, I felt pretty confident that I knew most of what was available in terms of support. As a graduate student, many years later, I was surprised to learn that Manitoba had legislated an Act to recognize informal caregivers. At first glance, it appeared to be an earnest attempt to value caregivers in policy documents, that would hopefully trickle down to the everyday practices of home care workers and service providers. Despite my optimism, it did not appear this was the case. It is not enough to say that Manitoba includes caregivers in policy, without critically investigating the impact of this inclusion on caregivers. Thus, in the context of this research study, it is important to see if other caregivers had heard of the Act, and gauge their responses to its principles and goals.

As outlined above, in Manitoba, and in Canada, there have been waves of support and attention paid to informal caregivers in ways that enact neoliberal discourse. While they are starting to be recognized in both research and policy, research is needed to investigate how this attempt to engineer the subjectivity of caregivers actually plays out in the lived experience of caregivers. Additionally, there is a general understanding of the types of work done by informal

caregivers (Chapell & Hollander, 2005; Montgomery, 1999; Mong, 2020), the types of support that they would like to receive (Guberman, Lavoie, Blein & Olazabal, 2012; Khayatzadeh-Mahani & Leslie, 2018; Lilly, Robinson, Holtzman & Bottorff, 2012) and how they feel about caregiving in general (Forbes & Edge, 2009; Guberman, Lavoie, Blein & Olazabal, 2012). However, what is missing from the literature is a theoretically informed understanding of how informal caregivers interpret their sense of self, and sense of 'home' while receiving home care. The following sections summarize existing literature regarding adaptations that need to be made to sites of care (i.e. homes) and to the informal carers themselves, to allow the home care system to provide services.

2.4 Preparing and Adapting the Home for Home Care

Home and built environments have been recognized by the World Health Organization (WHO) as having "a crucial role in promoting health ageing and ensuring no older person is left behind" (2021, p. 67), thus more attention is being paid to the ways in which older adults, particularly those with chronic conditions, can be supported in their homes. Having a safe and stable home is essential to this, yet there are inequalities in access to adequate housing, and special attention should be paid to environments with poor infrastructure (Keating, 2022). For those housed and able to receive home care services, sociological research on spatial embodiment and the experience of home (Tamm, 1999; Buse & Twigg, 2014; Jacobson, 2009; England & Dyck, 2011) has found that receiving medical services in the home blurs the boundaries between the public and private sphere. Home is not just a location, building, or material artifact; it is relational (Boccagni & Kusenbach, 2020). Feeling 'at home' is significantly impacted by the relationships within it and our desire to have a sense of security, familiarity and control over our lives (Boccagni & Kusenbach, 2020, p. 597). Therefore, home is "a process rather than a state of

things" (Boccagni & Kusenbach, 2020, p. 597). As such, when new people or structures, such as home care, enter the home, our construction of home, both physical and emotional, may change (Dyck et al., 2005). Of particular relevance for my study, families may lose some control over the arrangement of the home space if certain services and technologies are required (Glasdam, Henriksen, Kjaer & Praestegaard, 2013). As described by Tamm (1999), the "older a person is, the more meaningful the things in the home are perceived to be" (p. 51). A home is a place that provides sanctity, solitude, and protection from the outside world (Tamm, 1999). As suggested by Glasdam et al. (2013),

> "A home is more than a place to live. A home has symbolic functions in the way we arrange the furniture, the colours, the art works and the decor we choose to frame and narrate our lived life by. A home is a private place, usually separated from the public space. All this changes when a person receives home care. Both the professionals and the client seem to be caught between the working conditions of the professionals and the client's way of constructing his home and life. In that way, the professionals bring the institution into the home and thus institutionalise and medicalise the home" (p. 336).

There is, however, an inherent tension between the idealized meanings of home and the lived negotiations that shape it, often referred to as 'the contested space of home' (Mallett, 2004). Even without the complicating factors of the medical model or medical professionals, home is not a singular entity but is a multidimensional and often contradictory space that simultaneously combines security and belonging, with, in some cases, exclusion or control (Mallett, 2004). This complexity is refined by the home's status as an "essentially contested concept" (Gallie, 1955, p. 196), meaning its definition is continuously disputed and shaped by competing values and political positions (Meers, 2023). Within daily life, the boundaries between work, care, and rest, are continually negotiated, leading home residents to adopt various strategies, such as containment and exclusion, to protect or reclaim their private space from others within the home (Santos et al., 2024). For many, home is not understood as a haven, but an actively negotiated

space where ideals of togetherness coexist with struggles over autonomy and control (Santos et al., 2024).

Allowing the medical model into this private realm can transform this already contested space into "a disabled person's dwelling" (Tamm, 1999, p. 51), and thus can ignore or mitigate the complex negotiations and experiences of the other members of the home space. Ironically, as the home "increasingly becomes the core site of everyday life for those whose mobility and activities are constrained, it also becomes its most 'public'" (Dyck et al., 2005, p. 181). When home care services enter the home, this can "disturb the established meanings and routinized activities that constitute the lived home" (Hale, Barrett, & Gauld, 2010, p. 32) by making the home a workplace. This is done through opening the home to the scrutiny of the medical gaze, the adaptation of the home, and the introduction of medical technologies (Dyck et al., 2005).

In contrast to the standardized and bureaucratic nature of hospital environments, the irregularity and unpredictability of the home environment has led to an increase in adverse events for recipients of home care in Canada (Blais, et al., 2013). Thus, in the spirit of risk reduction, the home is evaluated for risks by professionals deemed experts in their areas, including occupational therapists and case coordinators, and appropriate interventions must be applied before a patient is released from the hospital. Similarly, those who initiate home care from their homes must also be assessed by the same professionals. In effect, the ontological security of the home may be undermined. As found by Dyck et al. (2005), the "re-ordering and re-inscription of homespace as a site of care is underwritten by relations of power" (p. 182) whereby health professionals are deemed knowledge experts.

Often during this process, the recipient of care and other members of the home have little control over the decisions being made (Hale, Barrett, & Gauld, 2010). "Treatments ordered by

the physician and personal physical care have priority over psychological and social needs from the position of professionals. It indicates that medical logic is the underlying thinking that rules home care, even though the physician is physically absent" (Glasdam, Henriksen, Kjaer & Praestegaard, 2013, p. 333). This suggests that medical needs are more important than the home space, or the social and psychological wishes of the person receiving care. In contrast with hospitals, homes are not designed to be sites of regulated medical care, therefore medicalization of the physical private space must occur, within this logic.

As an example, homes do not have to be as sterile as hospitals, and each person has different expectations of cleanliness within their home. However, in Mong's (2020) qualitative study of informal parental caregivers, she found many caregivers may clean their homes to the point of excess to ensure germs are not present. This excessive cleanliness also extended to members living outside the home, including guests and repairmen, who were asked to remove their clothing before entering the home (Mong, 2020). Although care workers are instructed not to comment on the cleanliness of the home, some mentioned that dirty home environments impeded their ability to provide quality care, and thus needed to report the home and family to a supervisor (Mong, 2020).

A *Home Safe Home* (CAOT, 2017) approach has been adopted by Canadian occupational therapists to minimize safety risks for persons receiving care (Government of Manitoba, 2017). However, these adjustments may change the home by constructing it as a site of health risk. Making the home safer can include minor adjustments such as minimizing clutter, installing bright lights, and having a bathmat, or chair in the bathtub (CAOT, 2017). More invasive forms of medical technologies into the home can include installing a ramp or wheelchair lift to the entrance of a home or staircase and installing safety handles and bed rails (Shafir, et al., 2016).

In some cases, ‘high tech’ equipment such as respirators, hoists, and hospital beds are brought in to replace the bed of the patient (Stall, 2019). In these ways, the private space of the home is adapted to more closely resemble, in many people’s eyes, the regulated public space of a hospital. Although some of these adaptations may seem inconsequential, the familiarity of the home space is being altered, “the older person has to re-learn his/her environment, which could be a challenging task, fraught with strangeness, anxieties, and uncertainty” (Hale, Barrett, & Gauld, 2010, p. 34). Therefore, patients are not released from the hospital into the comforts of the home they remember.

Specifically, caregivers in Mong’s (2020) study expressed distress over trying to keep the ‘hospital environment’ separate from the ‘home environment’ and keeping other family members (such as young children) out of the medical supplies. Although some kept the environments separate, many relaxed the delineation of medical and non-medical spaces to create a hybrid (Mong, 2020). For example, a caregiver joked that her son’s medical supplies were now kept in the fridge in the garage alongside the beer (Mong, 2020, p. 75). An additional concern of caregivers providing care at home is simply that the layout of the home is not suitable for medical supports. Caregivers living in smaller homes or apartments have had to rearrange their homes, or move homes altogether because there is no space to provide care (Mong, 2020). Although Mong (2020) referred to caregivers as “clever” (p.75) in some of the ways they adapted their homes, this is still an example of adhering to the medical model by making significant changes.

Similar to the findings of Mong in their qualitative study with live-in caregivers in Ontario, England and Dyck (2011) also noted the blurring of ‘home’ and ‘workplace’ when home care services are introduced. The home, as both a domestic and professional space,

becomes layered with complex meanings, particularly when personal environments, in particular, bedrooms and bathrooms, become sites for intimate care like lifting, undressing, and administering catheters (England & Dyck, 2011, p. 211). Providing care in these spaces goes beyond that of 'normal social interactions' and crosses a boundary of 'privacy' (England & Dyck, 2011). Complicating matters further, care is often delivered across multiple households, and each home effectively becomes a different workplace, requiring home care workers to constantly negotiate new spatial, social, and emotional boundaries. This transgression of bodily and private space redefines what 'home' means, not only for the care recipient but also for family members, some of whom reported leaving the house during care visits because they felt their home had been "transformed into a paid workplace" in which they no longer felt comfortable (England & Dyck, 2011, p. 211). The result is an ongoing tension as the once accepted meaning of home (Santos et al., 2024) is continually reworked in the presence of professionalized care.

Although medical technologies can help individuals remain more independent in their homes for longer periods of time, these technologies are only beneficial until something does not go as planned (Spring et al., forthcoming). For example, compression stockings will only help an individual if home care workers are available at the right time of day to put them on and take them, off, thus highlighting the reciprocal and relational nature of care (Spring et al., forthcoming). It has also been found that, if changes were not made to the home, families were viewed as hindering the safety of the patient, regardless of whether they felt the adaptations were necessary (Benzein, Johansson, & Saveman, 2004). These spatial disruptions (Hale, Barrett, & Gauld, 2010), although potentially beneficial for the patient, can perpetuate the surveillance of the population by reinforcing the fear of 'risk' within the home. As explained by Glasdam,

Henriksen, Kjaer & Praestegaard (2013), visible signs of dependency can be very hard on recipients of care and family members who live in the home, remarking that medical technologies and adaptations can be "a sign of incurable illness and misery" (p. 355). Individuals living with the patient are also affected by the medical adaptations made to their home (Tamm, 1999; England & Dyck, 2011). They may feel as if their private space is being invaded and must adapt to medical prevention measures that are not intended for them (Tamm, 1999).

Glasdam, Henriksen, Kjaer & Praestegaard (2013) also found that "the more dependent the client is on the professionals, the lesser influence he has on his everyday life" (p.333). To elaborate, the more reliant the recipient of care became, the less workers would go 'above and beyond,' instead simply sticking to the tasks on the task sheet, because he felt his dependence minimized his autonomous sense of self. This gave the recipient of care fewer options for how he wanted to structure his day (Glasdam, Henriksen, Kjaer & Praestegaard, 2013). The only event that would allow the care recipient to deviate from the schedule was his unpredictable toileting needs (Glasdam, Henriksen, Kjaer & Praestegaard, 2013). Thus, Gladsam et al., (2013) argue that "home care service acts as a disciplining practice in modern society" (p.83).

As these examples show, relying on home care workers does not always foster the improvement of a patient's health, but instead may lead to increased compliance and dependence on the medical model. As found by Glover and Harman (2000), home care services may "force families into a medical model to receive even supportive services in their homes" (p.319), which can sometimes lead to an embellishment of medical needs. Consequentially, patients may learn to define themselves in terms of what they *cannot* do, instead of what they *can* (Hale, Barrett, & Gauld, 2010). In addition, medical technologies in the home, particularly when they are new, can

serve as reminders and symbols of disability, thus impacting the self-esteem of the patients, and reinforcing the stereotype of the elderly and disabled as 'helpless' (Tamm, 1999).

A key feature of the home is the ability of the occupant to determine who can enter the home and when (Callopy, Dubler, & Zuckerman, 1990). However, home care blurs the boundary between allowing carers into the home as workers and welcoming carers in as guests. Aronson (2006) found that some care recipients felt the need to clean up their homes and make themselves look presentable before 'guests' (home care workers) arrived, even if they were receiving help with housekeeping and personal hygiene. Recipients of care did this to maintain a sense of pride and dignity in their homes and a sense of self-worth while minimizing notions of dependency (Kuryk et al., 2024). Many care recipients still wanted to present their best selves to the workers and demonstrate that they are still capable of living in their own homes (Kuryk et al., 2024), especially when care recipients were having to "expose" their homes and selves to a "succession of strangers" (Aronson, 2006, p. 407).

Trust is also a major concern when choosing to accept medical professionals into the home (Cooper & Urquhart, 2005). Granting elements of control to a medical professional makes family members, as well as the patient, vulnerable to the consequences of their actions (Leiknes & Hoye, 2012). Family members need to be confident that the workers are competent, and are providing high quality care that enhances the quality of life of the patient. It can be hard, however, to establish trust due to frequent staffing changes (Winslow, 2003). This can make it difficult to establish a care routine, and maintain the dignity and independence of a patient at home when they are constantly being introduced to new workers. Aronson (2006) found that care recipients felt diminished and disrespected when service was inconsistent. For example, an Ontario senior in a study conducted by Aronson commented on having her catheter changed by

numerous workers saying: “you have no pride. I mean you have no dignity. There’s nothing to it because I mean you have these strangers coming in and looking after you in very personal places...and you have no choice” (2002, p.18).

Introducing new homecare workers also increases the number of people that have access to the medical records, and the private home of the patient. Multiple ‘strangers’ in the home impede the privacy of other residents in the home, for whom the care is not intended. Often, it is not just one worker that cares for a care recipient but could be a different worker every day, or different workers coming at multiple times throughout the day (Aronson, 2006). While this may be a feature of bureaucratic systems in general, it also highlights the objective and ‘machine-like’ nature of the medical model, wherein one individual (worker or patient) can be swapped for another with little regard for the individual themselves (Freund, McGuire & Podhurst, 2003).

In addition to having multiple new medical providers coming into the home, the people already living in the home may experience changes to their lives, tasks, and social roles when home care services are required for someone they live with. This literature review concludes by outlining the ways in which family/friend caregivers transition to quasi-medical providers when home care services are provided in their home.

2.5 From Family Member to Medical Provider

Receiving home care services can be a big adjustment for the recipient of care, but also impacts the live-in caregiver as well. The first step in the process of obtaining home care services is the physical home assessment. Following this, the second step is scrutinizing the availability and willingness of family members to provide care. This can be one of the most difficult processes for the caretaking family members (Bookman & Kimbrel, 2011). Mong (2020) found that,

> "Family caregivers *do* [emphasis in original] have paid supervisors monitoring and evaluating their work, and their emotions are evaluated by home health nurses, as in cases in which their attitudes toward care recipients are not deemed caring enough" (p.96).

This suggests that caregivers may be internalizing the requirements of the medical system, through a process known as biopower (Foucault, 2003), to ensure they are viewed as competent caregivers by the standards of the medical model. Family members may also feel a responsibility and obligation to care for their relatives (Winslow, 2003), and may blame themselves for not working hard enough to provide the support that is needed (Leiknes & Hoye, 2012). Some family members may be resistant to home care, simply because they "are unwilling to let 'strangers' (caregivers) in the home" (Winslow, 2003, p. 345).

Recipients of care themselves may also resist home care because they feel they are becoming dependent, and losing the autonomy to direct their own lives (Winslow, 2003). Once again, this can put family members at odds with what is recommended by the 'medical experts', and what they feel is best for their family member. Similarly, Cooper and Urquhart (2005) suggest that allowing home care into the home may increase the care recipients' family members' reliance on home care services and increase dependency. For example, they found that many family members of home care recipients ask questions of home care workers regarding service offerings or medical advice, instead of seeking the information for themselves (Cooper & Urquhart, 2005).

The type of services, needs of the patient, and the amount of service required by a patient at home are ultimately determined by the home care plan which must be in place before leaving the hospital, and agreed upon for those who are accessing services initially from the community. In other words, medical professionals are influencing the life of the patient, as well as the lives of the patient's primary caregivers (Tamm, 1999). The times that homecare services, such as

respite, will be provided can influence the hours that family members work, and the types of hobbies they pursue in the evenings (Leiknes & Hoye, 2012; Mong, 2020). In Western Canada, there has been a trend towards standardization of care tasks and time allotments, which limits flexibility and accommodations that could be made to better fit the needs of the patients and families (Bjornsdottir, 2009). Standardization does not allow for adaptability to emergencies, and families are often required to apply for additional care at least a few days in advance.

A strict home care schedule can make accommodations difficult for caregivers who work part-time hours or shift work (Mong, 2020). For example, respite services provided by home care in Manitoba are only available up to 40 hours a week (Government of Manitoba, 2015). Therefore, family members may be able to work a 40-hour work week, but will not be provided with any weekend respite; when they might need the relief the most. It has also been found that family members who rely on respite during the day are less likely to pursue hobbies in the evenings because of the guilt they feel for not being with their loved ones during the day (Leiknes & Hoye, 2012). This evidence suggests that the surveillance medicine (Armstrong 1995) aspects of homecare may influence the activities of the larger population by determining when caregivers should be at home providing care.

Even when services are put into place, "homecare does not take away the feeling of being on-call around the clock" (Leiknes & Hoye, 2012, p. 8). It can be hard for family members to feel as if the burden of care is lifted, as they must balance their own lives with the needs of the patient (Leiknes & Hoye, 2012; Mong, 2020). The time required to care for a variety of different medical conditions often does not fit with inflexible homecare schedules. For example, patients with Parkinson's Disease require medications every few hours, but this may not fit into a home care worker's schedule (Leiknes & Hoye, 2012). Thus, family members need to be available

themselves to deliver the medications, and at all other times during the day in case of an emergency (Shafir, et al., 2016).

In addition, because many home care providers are short-staffed, family members need to be available to care for their loved ones if a home care worker is unavailable. The unreliability of home care due to understaffing is a major stressor that is experienced by family caregivers (Winslow, 2003; Mong, 2020). Therefore, through the use of home care services, the gaze of the medical model may extend beyond the patient and allows the patient's primary caregivers to be observed, and their lives to be altered as well. Spring et al. (forthcoming) found that workers in the home "can also be the source of discomfort for clients who feel judged for their housekeeping and use of personal space" (P.XX). Additionally, Spring et al., (forthcoming) note that having workers in the home, even routinely, can impact that "natural flow of relationships" (p. XX) within the home, between and amongst all those residing in it. Changing the social role and lifestyle of a patient's caregivers are not the only consequences of home care services; the home of the patient must also often be altered to adapt to the Western medical model of care.

Finally, as home care becomes more focused on medical tasks and less focused on emotional, supportive, and homemaking tasks, the work done by caregivers is also often becoming more technical and advanced (Mong, 2020), and "what was once perceived as solely professional health activities become the responsibility of the patients and family members" (McDonald et al., 2016, p. 2181). In addition to helping a loved one with activities of daily living, and instrumental activities of daily living, family caregivers may also have to undertake skilled medical work including, but not limited to, giving injections, cleaning and changing ostomy bags and catheters, wound care, tracheostomy care, and managing feeding tubes. Mong (2020) suggests that "caregivers come into the medical labour process because of their

relationship to care recipients, not because of their proclivities toward this highly specialized work or their initial skills" (p. 55). Ironically, as the requirements to become a nurse become more stringent, the scope and complexity of medical work done by family caregivers continue to increase, often without additional training (McDonald et al., 2016; Mong, 2020). It was found that caregivers lack access to hands-on training to support the teaching of complex medical and personal tasks (McDonald et al., 2016; Stall, 2019). The relationship between caregiver and care recipient may change from family member to health care provider which can impact the identity of both (Mong, 2020). Finally, the work of learning and managing a medical task is ongoing, as caregivers providing complex medical tasks for loved ones at home often felt "they were both 'becoming' and 'being' an expert" (McDonald et al., 2016, p. 2180) at the same time.

Privacy of the recipient of care becomes an additional concern when their medical records and private living space are being placed in the trust of the medical model. Privacy is a culturally determined concept, which is the state of being free from observation or being disturbed (Bates, 1964). Bates argues that privacy can be constructed in three different ways: privacy of the self, including one's emotions and beliefs, privacy from an unwanted intrusion of someone else, and privacy in different situational contexts such as privacy within the home (Bates, 1964). Because the "home is a crucial material and symbolic source in the construction of personal identity" (Hale, Barrett, & Gauld, 2010, p. 31), this definition of privacy extends to one's surroundings. One's definition of privacy and limits to openness do not change quickly, because privacy is a concept that is intimately related to selfhood (Bates, 1964). However, Bates notes that loss of privacy is expected in the patient/physician relationship "only with the understanding that it will not be allowed to harm a person who thus makes himself vulnerable to another" (Bates, 1964, p. 432). This bargain obliges the physician to "not reveal what is learned

in any way which further reduces that privacy" (Bates, 1964, p. 432). However, in the new *family-centered* care approach, the 'patient' side of the relationship is extended beyond the patient to include their primary caregivers, possibly enrolling the privacy of the patient's family into a web of medical surveillance.

Often, when families are deciding what is the best option for the patient regarding long-term care, a team of medical professionals is assigned to help (Benzein, Johansson, & Saveman, 2004). In Manitoba, when being discharged from hospital, this team includes doctors, nurses, pharmacists, occupational therapists, physical therapists, home-based case coordinators and hospital-based case coordinators. In Manitoba when entering the home care program from the community, the team includes a general practitioner, resources coordinator, case coordinator, and occupational therapist. Privacy of the patient's medical history and adaptive needs are scrutinized by a team of medical experts and service professionals, which is outside the realm of the patient/physician relationship. It can be said, therefore, that the patient/physician relationship is abandoned, when physicians no longer respect a patient's privacy (Parrott, Burgoon, Burgoon, & LePoire, 1989; Bates, 1964). Although still distributed on a need-to-know basis, the amount of personal and social information about the care recipient continues to be shared with an ever-increasing number of health care professionals and service providers. Thus, health information is no longer kept between the patient and doctor or nurses, but rather is discussed with a wider network of professionals.

In addition, the imposition of a 'team' reaffirms the Western medical model whereby medical professionals are viewed as 'experts' (Benzein, Johansson, & Saveman, 2004), and the knowledge held by the patient's family becomes secondary. "Professionals and para-professionals alike are perceived to have societally assigned knowledge, status and power over

those requiring services" (McWilliam, et al., 2014, p. 212), thus the process should be to work *with* family members instead. However, if family members choose not to take the advice of medical professionals (and by extension advice of the Western medical model), they are often viewed as a challenge for medical practitioners and are considered to be hindering the well-being of the patient (Benzein, Johansson, & Saveman, 2004). When conflicts of interest arise, families are often disqualified from assuming decision-making roles (Arras & Dubler, 1994).

In cases where families are involved in decision-making, Dubbin, Chang and Shim (2013) found that providers only viewed family members as 'true partners' when they were able to reach a 'shared understanding' (p. 9). Dubbin et al. (2013) concluded that 'shared' effectively meant a "biomedical understanding, and the capacity to use language, ask questions, and deliver information based on that biomedical understanding" (p. 9). Thus, only family members willing to adopt a biomedical worldview could actively participate in decision-making. In addition, they found that medical practitioners are less likely to 'waste time and resources' on patients who are seen as neglectful of their medications or of furthering their care (Dubbin, Chang, & Shim, 2013). Therefore, family members who do not embrace the process of medicalization may be targeted by disciplinary practices that exclude them from making important decisions or be at risk of losing services which may impact the well-being of the care recipient.

In contrast, families that are involved in the medical process, and take the advice of the 'medical experts' are perceived as resources that are beneficial to the care of the patient (Benzein, Johansson, & Saveman, 2004). The acceptance of the medical model can therefore put families in a difficult position between doing what they believe is the right approach to caring for the patient, and what is forcefully recommended to them by the 'team of medical professionals'.

Additionally, McDonald et al. (2016) and Mong (2020) found that family caregivers performing medical tasks for their children often look to medical outcomes or doctors' assessments of their care performance as a test of their abilities. This may reinforce the medical model by taking power away from caregivers, as they place more trust in medical professionals. Mong (2020) also found that caregivers who rely on doctors' assessments may experience additional stress and worry that they are not performing serious procedures correctly. McDonald et al. (2016) found caregivers experienced uncertainty in their abilities as "boundaries were not absolute…and professionals judged [if] they were competent and a sufficiently safe environment could be created" (p.2177). Even for tasks they once performed without difficulty, this looming sense of doubt made caregivers feel "nervous" and "want the reassurance of health professionals" (p.2177).

The reliance on medical professionals' approval is an example of social iatrogenesis (Illich, 1976). Iatrogenesis refers to the harm that is caused to individuals by medical intervention (Illich, 1976). With the expansion of surveillance medicine into everyday life, Illich argues that the overreach of medical institutions can lead to various forms of iatrogenesis. Illich suggests there are three forms of iatrogenesis: clinical, social, and cultural. Clinical iatrogenesis occurs by direct harm through unnecessary treatments, side effects and medical errors (Illich, 1976). Social iatrogenesis suggests that medicalizing every aspect of life undermines the individual autonomy of individuals, requiring them to rely on 'expert' opinions (Illich, 1976). Cultural iatrogenesis argues that medical explanations can undermine cultural and personal ways of managing everyday aspects of life (Illich, 1976). Thus, it is essential to acknowledge the harms that may befall individuals by becoming increasingly reliant upon medical discourse, and by extension, the harms caused by the home care system to those in which it provides support.

Following the suggestion of Conrad (2013), it is the role of sociologists to unpack the social consequences of medicalization. It was found by Spring et al., (forthcoming) that "the home, where an older adult client prepares and eats meals and is supported by varying medical devices, is not only a site of health care service delivery; it is an encoded assemblage of meanings built on the material and relational cultures within" (pg. XX). Thus, my research seeks to understand how home care services and service providers medicalize the private sphere of the home and the family members who reside in it. Foucault suggests (1975) that universal objectives do not exist but instead exist in a web of similar and relational entities. For example, the act of 'caring' does not exist in its own right, but exists within a set of relationships, expectations, and abilities. To better understand these dynamics, the following chapter will outline the theoretical foundations of this study, focusing on the concepts of medicalization and surveillance medicine. Drawing on Foucault's ideas of power, discipline, and biopolitics, as well as Conrad's framework of medicalization, the next chapter will examine how medical authority extends beyond clinical settings into homes and family relationships. Through this lens, we can critically analyze how caregivers navigate the increasingly blurred boundaries between personal responsibility, medical expertise, and institutional control.

Chapter 3: Theory – Medicalization and Surveillance Medicine

The concepts of medicalization and surveillance medicine provide a nuanced theoretical foundation for understanding the dynamics of home care. By drawing directly on Michel Foucault's later works on disciplinary power and the medical gaze, and Foucauldian-inspired studies of medicalization informed by David Armstrong, Nikolas Rose and Peter Conrad, in this

chapter, I will demonstrate how these conceptions describe the transformation of private spaces, such as one's home, into sites of medical intervention and control.

Medicalization is the process whereby "a problem is defined in medical terms, using medical language, understood through the adoption of a medical framework, or 'treated' with a medical intervention" (Conrad, 2007, p. 5). The sociological question concerning medicalization is not whether the condition is actually 'medical' (Conrad, 2007); what matters are the *effects and consequences* that 'making something medical' can have on the individual, and the institution of health care (Conrad, 2013). However, even conditions that are 'obviously' or 'biologically' medical can go through the process of medicalization (Fries, 2020). Defining a condition in medical terms places the term and the individual experiencing the condition under the gaze of medicine (Armstrong, 1995; Rose, 2001). Once a condition has been 'made medical', medical professionals have the ability to define, diagnose, and treat it. Foucault's concept of the 'medical gaze' (Foucault, 1975) describes the manner in which medical knowledge seeks to define and regulate subjects.

Foucauldian studies of health and medicine (Armstrong, 1983; Fries 2008; Turner, 1984/1996;1995; Peterson & Bunton, 1997; Jones & Porter, 1998; Frank & Jones, 2003; Rose, 1998) have made clear how it is that formal health care has changed and developed through time, and that medical knowledge "is socially constructed and changes with social and cultural transformation" (Segall & Fries, 2017, p. 315). Further, it is through societal and cultural changes that medicine became a way of knowing (Rose, 1998). While we were once dependent on the authority of religion or traditional morality for guidance and knowledge, we now rely on "'experts of subjectivity' who transfigure existential questions about the purpose of life and meaning of suffering into technical questions of the most effective ways of managing

malfunction and improving 'quality of life'" (Rose, 1998, p. 151). Thus, it is important to understand how home care, as an 'expert of subjectivity', is currently constructed in a time when neoliberalism dominates the social space.

Power is a central feature of Foucauldian theory, and Foucauldian scholars of health and medicine recognize that biomedical dominance is not always top-down. Instead, Foucault suggests that power is pervasive and productive (Foucault, 1982). In his words, "power is not as a negation of the vitality and capacities of individuals, but as the creation, shaping and utilization of human beings *as* subjects. Power…works through and not against subjectivity" (Foucault, 1982). In this way, power is not perceived as oppositional or top-down, but instead permeates all practices "through which persons are ruled, mastered, held in check, administered, steered, guided, by means of which they are led by others or have come to direct or regulate their own actions" (Rose, 1998, p. 152). As the directions of power become more complex, it is "the ambiguous set of relations between human subjects and political power" (Rose, 1998, p. 152) that allows for the governing body to 'conduct the conduct' of its human subjects (Rose, 1998).

Michel Foucault's (1978) concept of biopower suggests that power is dispersed throughout social relations. Unlike a pyramid, biopower can be conceptualized as an interconnected web with power flowing in multiple directions to numerous outlets. As explained by Brown (1995), "rather than a given biomedical fact, we have a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux" (p.37). In this way, power is embedded in structures of knowledge and visibility (Foucault 1975). The knowing, seeing, and categorizing of subjects is central to disciplinary power, allowing for dominant discourses to control the subject. Foucault uses the 'medical gaze' (1975) to describe how medical professionals objectify patients; separate

the person from the illness, observe and analyze patients in a detached manner, and ultimately reinforce medical authority as the elite discourse for understanding oneself. My research will consider home care's role in these social processes by extending the medical gaze beyond the individual to their surrounding environment.

Medicalization is not merely about the expansion of medical categories but also involves the creation of new illnesses and the redefinition of normality (Conrad, 2007). Foucault (1975) in *The Birth of the Clinic* illustrates how the classification of diseases and the standardization of diagnostic practices contribute to this process. The home, as a site of care, becomes an extension of this medical domain, where caregivers and patients alike are subjected to the medical gaze, thus it is important to understand how the home became a site of medical interference. Before the golden age of modern medicine, Bedside Medicine was the model of medical care which was dominant (Armstrong, 1995; Jewson, 1976). With Bedside Medicine, the patient was treated at home, with a focus only on the relationship between symptoms and illness (Armstrong, 1995; Jewson, 1976). The needs of the patient were dominant, and they decided upon their cure and the effectiveness of their physicians (Jewson, 1976; Segall & Fries, 2017). Thus, despite the home being the location of care, the situational power resided with the recipient of care, who needed to be impressed by the physicians' medical expertise (Jewson, 1976). Foucauldian scholarship shows how this mode of production of medical knowledge was replaced by Hospital Medicine, whereby pathology was included in the framework, therefore allowing for a three-dimensional relationship (Armstrong, 1995). Hospital Medicine was practiced "in the 'neutral' space of the hospital so that the indicators of the underlying lesion might be properly identified without the contaminants of extraneous 'noise'" (Armstrong, 1995, p. 395). In this mode of production of medical knowledge, the needs and knowledge of the patients were supplanted by the knowledge

of medical experts, thus removing patients from being active participants in their care (Armstrong, 2008; Jewson, 1976).

According to the Foucauldian history of medicine, following Hospital Medicine, Laboratory Medicine was introduced, wherein the location of illness was found in the cells of the individual, thus entirely separating the person from being active in their care (Jewson, 1976). Although Hospital and Laboratory Medicine dominated the Western medical model for the last two centuries, Surveillance Medicine has since emerged (Armstrong, 1995; Foucault, 1963). Armstrong (1995) suggests that Surveillance Medicine extends the medical gaze beyond the individual when an illness appears to monitor their behaviours and lifestyle in the name of prevention. According to Foucault (1963), surveillance medicine uses a risk-based approach whereby the population is viewed as constantly 'at-risk' for an illness. This 'pre-at risk state' (Armstrong, 1995) allows the medical gaze to extend its authority into other aspects of an individual's life, blurring the boundaries between health and illness. Medical surveillance becomes internalized by the individual and they begin to 'self-surveil', thus normalizing the authority of medical discourse in everyday life.

Medicalization scholars suggest that medicalization functions as a mechanism to separate and categorize the healthy from the sick, and by extension, the normal from the abnormal (Turner, 1987; Armstrong, 1995). Foucault theorizes that problems, and problem subjects, only arise when they are viewed as such. When someone, or something, is constantly identified as a problem, "'problem subjects' are forced to reflect on their own identity and their own practices, and ideally will bring themselves into line with social norms" (Schirato, Danaher & Webb, 2012, p. 166). Foucault (1988) describes this as 'technologies of the self' whereby individuals, through the help of governing bodies, are able to "transform themselves to attain a

certain state of happiness, purity, wisdom, perfection or immortality" (p. 18). Subjects that are willing to self-surveil and bring themselves back in line with social norms are viewed as 'good subjects', and what currently constitutes 'good' is determined by the elite discourse of medicine.

For Foucauldians, such as David Armstrong (1995), beginning in the twentieth century, with the rise of medical technologies, there has been a reconfiguration of the space of illness. This means the location of an illness has changed, from outside the individual, to within the individual, to within the cells of the individuals, and finally to the surrounding spaces of the individual (Armstrong, 1995). This changing spacialization has led to 'surveillance medicine' (Armstrong, 1995), whereby the three-dimensional relationship between symptom, sign, and illness, is extended to include extra-corporal and temporal space (Armstrong, 1995). This first began with 'self-surveillance', when sanitary medicine and personal hygiene were the focus of population health (Armstrong, 1993). Scientific medicine has discovered the relationship between health and environmental contaminants (Armstrong, 1993). It was relatively easy to monitor the hygiene of individuals in regulated spaces such as schools, hospitals and prisons, "but for the vast majority of the population the application of sanitary hygienic rules was less comprehensive" (Armstrong, 1993, p. 401). Legislation also could not penetrate the private sphere of individuals; therefore, a new regime of public health began, "which opened up the possibility of recruiting people themselves to the surveillance of body boundaries and anatomical spaces" (Armstrong, 1993, p. 401). This research investigates how home care serves this reconfiguration of the private sphere; opening it up to medical surveillance.

According to such a Foucauldian account, surveillance medicine penetrates the larger population, by reframing illness as a "pre-illness at-risk state" (Armstrong, 1995, p.401). The binary relationship between health and illness, in which health is constructed in opposition to

illness, is reconstructed on an "ordinal scale in which the healthy can become healthier, and health can co-exist with illness" (Armstrong, 1995, p.400). By promoting the at-risk state, the entire Western population can effectively be brought under a "network of visibility" (Armstrong, 1995, p. 395), and an individual's 'lifestyle' can now be closely monitored under the guise of bettering health (Armstrong, 1995). With disease and illness lurking around every corner, individuals are incited to live in a constant state of fear (Armstrong, 1995). Perhaps, one of the ways in which some individuals deal with this heightened risk consciousness is by enrolling themselves or their family members in state-provided home care services. Armstrong (1995) suggests that "the ultimate triumph of Surveillance Medicine would be its internalization by all the population" (p.400). Thus, it is no surprise that homecare is advocated by medical professionals and accepted by recipients of care and families as a way to manage the health of the sick and aging while gaining access to the private sphere of the home.

Foucault argues that "disciplinary power is working through sites such as schools and workshops to quietly coerce people into forms of behaviour and attitudes of mind amenable to the interests of these disciplinary institutions, and the more general social practices they helped constitute" (Schirato, Danaher & Webb, 2012, p.3). Foucault (1977) goes on to argue that these institutions are constructed in a 'technological way' that allows for the extension of, and subjection to, power. Rose (1997) suggests that 'technological' institutions "are embodied in the design and institutional space, the arrangements of institutional time and activity, procedures of reward and punishment, and the operation of systems of norms and judgements. They can be thought of as 'technological' in that they seek the calculated orchestration of the activities of humans under practical rationality directed towards certain goals" (p.152-153). For example, home care may be understood from this perspective as an institution of disciplinary power that

seeks to produce and maintain medically 'well' subjects in ways that align with standardized policies and practices. Those who are medically well are viewed positively as contributing to society, and by extension, saving the state money by not being placed in an institution.

There are several ways of displaying disciplinary power throughout history. First, power was overt as a public display of strength to mitigate wrongdoings (Foucault, 1997). As time went on, the state moved from violent displays of power to more subtle surveillance-like control, making the body an ideal place for management. The exercise of the gaze is dynamic, allowing for different subjects to be enrolled as methods of surveillance. The gaze operates through a network of social relations with individuals acting as active mediators perpetuating the gaze (Foucault, 1963). Thus, power is not something that can be possessed but exists within a larger network. For example, when formal caregivers enter the home, they are perceived as providers and facilitators of the formal care network. Informal caregivers are then conscripted as supervisors of the care recipient, while simultaneously being supervised by the formal caregivers. In this dialectic of supervision "domestic and social relationships [are] made visible to practitioners" (Heaton, 1999, p. 772), extending the view of the gaze into the home. Additionally, Foucault views power as productive "in the sense that it shapes and moulds people, their dispositions and values, and their practices" (Schirato, Danaher & Webb, 2012, p. 46). Therefore, power is used to shape an individual to align with the needs of the state or governing institution. Most importantly, "[p]ower produces knowledge…power and knowledge directly imply one another…there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations" (Foucault, 1997, p.25). In other words, knowledge of a subjects' actions and

dispositions allows for power to extend its boundaries, while in turn also gaining additional knowledge.

Knowledge of a subject can be used to determine normality. Schirato, Danaher and Webb (2012) note that from a Foucauldian perspective, "subjects are continually evaluated in terms of their normality or otherwise of mental attributes, physical capabilities, feelings and attitudes, and sexual preferences" (p. 59). In terms of home care, workers may be able to measure the degree to which recipients have strayed from 'health' while also monitoring their adherence to the medical model. Foucault suggests that knowing a population turns them into "manageable subjects", a process to which he refers as the 'art of governing' (Foucault, 2007, 2008). Foucault goes on to suggest that knowable subjects allow for the production of policies that regulate the person for the benefit of the state (Foucault, 2007, 2008).

Foucault discusses the 'carceral continuum' whereby behaviour is organized and regulated through "bodies by the way they structure time, space, and relations" (Schirato, Danaher & Webb, 2012, p. 82). A Foucauldian perspective makes clear how, in many ways, the structuring of time, space and relations within the medical model bears striking similarities in one's home as they might to a prison or any other highly regulated public space. For example, a caregiver's time is not their own, and their space is assessed, monitored, and controlled by others. The relationships caregivers have with family are reconfigured, as is the authority of the home. Good behaviour is rewarded (following the rules and being ready and organized means that workers might have an extra five minutes to sit and have coffee) (Spring et al., 2024) and not following the rules and complaining too often may result in a reduction of services. According to Foucault (2007) "[f]reedom has to do with the possibility of movement, change of place, and

processes of circulation of both people and things" (p. 48-49). Therefore, it is essential to understand where caregivers feel they have freedom within the home care service.

Foucault's (1975) analysis in *The Birth of the Clinic* reveals that the medical gaze abstracts the individual from their illness, transforming the body into an object of scrutiny and intervention. This gaze is not confined to clinical settings but extends into various social spaces, including the home. The power of the medical gaze lies in its capacity to normalize certain behaviours and pathologize others, effectively controlling individuals through subtle and pervasive surveillance. It is through this effective use of power that institutions can "simultaneously problematize and transform" (Rose, 1998, p. 154) individuals toward particular ends. As suggested by England and Dyck (2011), "families reorganizsing their time and even their homespace to cope with their home as someone else's workplace" (p.217) required a "fine balance of the divisions of labour" and an established hierarchy. Through this lens, the body and the surrounding environment become a site of knowledge and power where medical professionals exercise control over health and illness.

The need for control and surveillance, Foucault (1975) suggests, is connected with liberalism. Rather than submitting themselves to be controlled by others or by the state, as self-governing subjects, individuals willingly surveil themselves to live in harmony with institutionally produced social norms. The relative invisibility of physical domination and outward displays of power presents subjects with a sense of freedom, although the end results are the same (willingly living as the state and institutions require). Although Foucault (2008) writes, "I am going to see to it that you are free to be free" (p. 63), it is argued that the conditions of freedom are only brought about as determined by the governing institution. Thus, freedom is only achieved within the boundaries of the policies and practices of the home care program,

making caregivers subject to surveillance within their own homes. As an extension of the medical model, home care can be conceptualized as an institution that promotes freedom while creating docile, manageable, and malleable subjects.

Rose (1997) suggests 'the family' has long been a target of 'technologies of self' as they are deemed 'private' yet are simultaneously sites of social consequences and duties. The movement of the medical model into the home suggests that informal caregivers and care recipients themselves may come to internalize the language, ideas, and practices that are central to the medical model, and thus continue to be targets of pervasive power. Internalizing the discourses and narratives of dominant institutions is essential to self-surveillance. By internalizing the practices of the medical model, informal caregivers may actually participate in the medicalization of their private space by embodying the role of caregiver. When changes are made to the home to remake it into a medical space, the family may feel "that the home no longer has the personal atmosphere that they associate with their home" (Tamm, 1999, p. 51). The question should not be whether a disease or illness is real, the question should be what are the consequences of defining and treating it in medical terms (Conrad, 2013), thus this research seeks to understand from the perspective of family/friend caregivers, how and in what ways they might experience their homes as medicalized. Additionally, I will consider situations where iatrogenesis could be theorized to have occurred due to medicalized expansion. Medicalization is one of the most effective means of social control (Busfield, 2017), thus it is essential to understand from caregivers themselves how recipients of homecare, their families, and their homes are being surveilled and controlled.

Chapter 4: Methodology

Using my sociological imagination (Mills, 1959), I wanted to better understand how my struggles being a live-in caregiver were similar or different to other caregivers and how this could be explained using sociological theories. Thus, I determined the best way to answer these questions was to speak as a peer with live-in caregivers of home care recipients. It was important, wherever possible, that these interviews be conducted in the homes of the caregivers so that I could immerse myself in their world. In addition to the interviews in the homes of the caregivers, I also asked to take pictures of their space to capture what they felt were important reminders of medical authority in their homes. My unique position as a researcher and a live-in family caregiver allowed me to connect with the caregivers in a novel way, and yielded information that outsiders would not have been able to gather.

The semi-structured interview model that I used focuses on how agentic subjective participants understand themselves within an objective social structure (Fries, 2012). Reflexive sociological interviewing is useful to discern "the cultural influence through which forms of medical knowledge come to be regarded as having the status of truth" (Fries, 2012, p. 3). Most importantly, reflexive sociological interviewing asks the participants to engage in reflexivity as they are asked what particular categorizing terms mean to them, instead of the researcher imposing analytical categories (Fries, 2012). The interview questions asked participants about how they define 'home', 'family', 'homecare' and 'caregiver', their experience as a family caregiver, how home care has impacted their home, how home care has impacted their relationship with the care recipient, and demographic questions, among others (see Appendix 1.0

for full interview guide). With participant permission, interviews were audio-recorded, and field notes were taken.

To minimize the power differential between myself (the researcher) and the live-in caregivers (the participants), it was important that rapport was established, and participants had some control over the interview process by guiding the flow and directions of the questions (Tracy, 2010; Wuest, 1995). In keeping with this, I shared my own stories in-depth and caregiving experiences with the participants to make it feel more like we were simply having a conversation, rather than engaging in an interview. I wanted them to understand that I was not just a researcher, but a caregiver, too. Additionally, I was conscious of how the participant was reacting emotionally to the process. In several cases, the interview was stopped (and the recording device shut off) while the participants took time to cry or reset themselves. We took time away from the interview for coffee and cake, as well as simply to hug and/or share a quiet moment with one another. I always asked if the participant was willing to continue with the interview process, and never recorded anything that they did not feel comfortable sharing.

I also engaged in an ethnographic analysis (Shaffir, 1999; Emerson, Fretz & Shaw, 2011; Kawulich, 2005; Hill, 2009; Brady, 2014). Although commonly associated with anthropologic research, ethnographies allow researchers to "enter the natural setting for the purposes of understanding the hows, whys, and whats of human behaviour" (Shaffir, 1999, p. 676). Being in the setting of the participants allows researchers an insider's perspective into the lives of participants (Shaffir, 1999). Ethnographic research also takes a departure from the neutral standpoint of many of the 'hard' sciences and instead allows the researchers to use their own experiences to build trust, rapport, and an honest relationship with participants (Shaffir, 1999).

When conducting ethical and meaningful qualitative research, it is essential that the researcher engages in a process of reflexivity (Tracy, 2010). Being reflexive in research means that the researcher is able to locate themselves within the data and determine how they relate to and/or impact the research process (Esterberg, 2002). Reflexivity is essential throughout the entire research process, from design through recruitment and analysis, to distribution (Wuest, 1998) and is an essential component of reflexive sociological interviewing (Fries, 2009). Reflexivity is an exercise in honesty and transparency (Wuest, 1995). Researchers need to do what they can, not only to acknowledge their place within the research but in some cases, reconcile it as well. My experience as a live-in caregiver benefitted the data collection and analysis phase of the research in ways I could never have imagined. As will be discussed in more depth in the following chapters, many participants mentioned how important it was to them that I understood what they were going through, and how me sharing my experiences helped them to open up about their own.

Brady (2014) argues that neoliberalism is often conceptualized as governmentality, but what is often missing is the context in which this occurs. Brady (2014) goes on to suggest that lack of context can be mitigated using ethnography which "allows for greater insights into the multiplicity of power relations and practices within the present" (p.13). Therefore, my experience as an informal caregiver added depth and highlighted particular contextual factors that non-group members lack. As suggested by Anderson (2006), "CMRs (complete member researchers) come closest of all…to approximating the emotional stance of the people in the study" (p. 380), thus I had an insider's look into the lives of caregivers. Additionally, my caregiving experience assisted in the data collection phase of research, as Foucauldian analysis

does not require objectivity as a key feature, but instead values subjective experience and constructivism (Hook, 2001).

4.1 Data Collection

I had the honour of sharing space and time with 13 family/friend caregivers from May 2022 through August 2024.[6] I was in awe of their sincerity and willingness to share their caregiving experiences with me. After receiving ethics approval from the Research Ethics Board at the University of Manitoba's Fort Garry Campus in April 2022 (HE2022-0061), recruitment began. The caregivers were recruited through social media posts on Facebook and Instagram, posters that were hung in various medical facilities throughout Manitoba, word of mouth, and on the Alzheimer's Society website.[7] Caregivers who were interested in participating in the research emailed, phoned, or texted me to inquire about the study and their eligibility. I would describe the research to the interested participants and ensure that the caregivers met the participation criteria. In some cases, potential participants were not eligible for the study because they were not living with the person for whom they were providing care, the person they were caring for did not receive home care, or the person they were caring for was not an older adult. If caregivers were not eligible for the study, I would still send them an email with a list of caregiver resources in case they needed extra support.[8] For eligible caregivers, I sent them an email with the consent form so they could read more about the study and what their participation expectations would be. Then, the caregiver and I scheduled an interview time that worked for both of us.

[6] I was on maternity leave from February 2023-January 2024.
[7] See appendix for 2.0 recruitment materials.
[8] See appendix 3.0 for list of caregiver support resources

For the present study, I spoke with two men, a husband and friend, and 11 women, including wives, daughters, a stepdaughter, and a granddaughter. All caregivers had been providing care for at least two years, while others had been caregivers their whole lives. All caregivers were over the age of 18 and consented to participate in the research. Twelve caregivers provided care in the Winnipeg Regional Health Authority (WRHA), and one caregiver lived in a rural health region. The tasks they provided included everything from 'simply' providing social support, to 24/7 hands-on caring that included managing the household, learning new medical tasks, and performing activities of daily living. The caregivers had a range of 1-6 years dealing with the formal home care system, including the public home care system, self-and-family-managed care, and private home care agencies. While some caregivers made modest changes to their home like adding grab bars in the bathrooms and bedrooms, other participants had to sell their home and relocate to a different space in order to provide care for their loved one.

Table 1: Participant Demographics

Caregiver name and age	**Relationship to care recipient**	**Time Caregiving**	**Time with Home Care**	**Primary condition**	**Tasks**	**Tasks of Homecare**
Johnathon, 40s	Friend	4 years	4 years	Mobility, intellectual disability	Personal care, cooking, cleaning, medications, and medical appointment, provides a place to live	Personal care, outings 3x a week - paused due to COVID-19 and never reinstated

Joanne, 60s	Daughter	6 years	5 years	Dementia	Cooking, cleaning, bathing, shopping, toileting, medications	Respite, pills, peri-care
Martin, 80s	Husband	6 years	3 years	Mobility	Cooking, cleaning, bathing, shopping, toileting	Morning/ night care, 2 days of respite
Amanda, 40s	Daughter	5 years	5 years	Mobility	Cooking, shopping, living space, laundry	4x daily, peri-care, meals, pills
Martha, 50s	Daughter	2 years	2 years	Dementia/ Stroke	Cooking, cleaning, bathing, shopping, toileting	Morning/ night care, lunch and dinner pills, PRIME for respite
Kendra, 70s	Step-daughter	2 years	2 years	Lymphoma, cognitive impairment	Cooking, laundry, social/ emotional support, cleaning, groceries	4x daily, peri-care, meals, pills
May, 50s	Daughter	20 years	2 years	Mobility	Cooking, laundry, social/ emotional support, cleaning, groceries	Respite/ meaningful social engagement
Georgia, 70s	Wife	16 years	1 year	Parkinson's Disease	Cooking, laundry, cleaning, dressing, ADLS, IADLS	Respite, 2-person assist
Maddison, 20s	Granddaughter	9 years	6 years	Dementia/mental health/ mobility	Emotional support/ quality time	Bedding, toileting, laundry, heat and serve

Katherine, 50s	Daughter	20 years/9 years	6 years	Dementia/mental health/ mobility	Meals, house-keeping, laundry, Drs appointments	Bedding, toileting, laundry, heat and serve
Rachel, 40s	Daughter	15 years	5 years	Multiple Sclerosis	Cooking, cleaning, appointments, dressing, bathing, managing incontinence, emotional support	Peri care, toileting, nursing care, respite
Tammy, 70s	Daughter	5 years	2 years	Loneliness, Mobility, early-stage Dementia	Cooking, cleaning, social support	Peri care, toileting, nursing care, respite
Pamela, 70s	Wife	2 years	1.5 years	PSP – (posterior supranucear palsy)	Meals, Drs appointment, house-keeping, walk dog, groceries	2x day peri-care

Due to Covid-19 and distance, three interviews were conducted via Zoom, while the others were done in the homes of the participants. On average, the interviews lasted 77 minutes, with the longest being 2 hours and 40 minutes. Additional time was added for home tours. During these home tours, I asked participants to walk me through their homes, particularly through areas where care was provided. I only went where the caregivers took me (I did not ask to see the whole home), and these spaces were most often the bathroom, bedroom, and living room. I would ask participants to describe to me how care was provided in these spaces, and by whom. If participants acknowledged a particular piece of technology, adaptation for, or barrier to providing care, I would ask to take a picture of it. The participants reviewed the pictures I took, to ensure there was no identifying information in them, such as family photos. The conversations

had during the home tours were not audio-taped, but recorded to the best of my recollection in my field notes.

These conversations revealed a wealth of information, stories, and emotions, and yielded nearly 1000 minutes of recorded conversation, 528 pages of transcription, 15 pages of field notes, and 20 pages of handwritten memos. Six of the caregivers consented to my taking photos of their home, and a total of 36 photographic images were captured (see table 2). Three of the interviews were conducted retroactively (the loved one they had cared for had passed away). One of the participants who retroactively discussed her experience of caring for her husband was not able to provide a tour of her home, but instead sent a scholarly article that she wrote comparing her lived experience with the narrative that dominates (particularly quantitative) research about caregiving. She asked that I include this document as part of my data.

As found by RANQ (2020), many caregivers are struggling to manage their caregiving role with their personal finances, a situation that has been exacerbated by the Covid-19 pandemic. In light of this, a small grocery gift card in the amount of $25 was offered as an honorarium to participants, however, some participants declined the gift card and asked that I donate the money instead to a local foodbank.

Audio recordings were uploaded to *Express Scribe Transcription*, a software program which allows recordings to be slowed down and controlled (stopped, played, fast-forwarded, rewound) with a foot pedal, and were transcribed by hand using *Microsoft Word.* Data transcription is an important first step for the researcher to immerse themselves in the data (Forbat & Henderson, 2005; Bischoping & Gazso, 2016), thus, I did not want to use a transcription service. Transcription is more than just notating content and can also be a creative process (Forbat & Henderson, 2005; Watson; 2006). Additionally, it is important in Foucauldian

analysis that the researcher not only attends to *what* information is shared but also *how* information is shared (Bryman, 2004). With this in mind, I ensured that my transcription was verbatim, including voice inflections, nuances, long pauses, and gestures (as described in the field notes).

Table 2: Interview Characteristics

Caregiver	Date	Number of Transcribed Pages	Duration of Interview	Number of Images from Home Tour
Johnathon	January 2023	89 pages	1 hr 47 min (107:22)	4
Joanne	March 2024	72 pages	2 hr 40 min (160: 54)	10
Martin	May 2022	27 pages	1 hr 1 min (61:33)	5
Amanda	October 2022	25 pages	1 hr 5 min (65:55)	0- conducted via Zoom
Martha	May 2022	43 pages	2 hr 16 min (135:52)	10
Kendra	May 2022	29 pages	1 hr 11 min (77:10)	2
May	November 2022	58 pages	1 hr 38 minutes (98:30)	0 - conducted via Zoom
Georgia	March 2024	34 pages	1 hr 11 min (77:00)	0- conducted retroactively

Maddison	April 2024	18 pages	33 minutes (33:44)	0 - conducted via Zoom, retroactively
Katherine	March 2024	30 pages	1 hr 4 minutes (64:14)	0- conducted retroactively
Rachel	April 2024	22 pages	44 minutes (44:31)	0- conducted retroactively
Tammy	August 2024	39 pages	53 minutes (52:56)	0
Pamela	August 2024	42 pages	1 hr 16 min (76:13)	5
N=		528	999	36
		40.6 pages on average	77 minutes on average	

4.1.a Speaking caregiver to caregiver: The impact of Complete Member Research

Analytic autoethnography is used when the researcher is a full member of the research group and is "committed to developing a theoretical understanding of broader social phenomena" (Anderson, 2006, p. 373). Following a Foucauldian theorization, analytic autoethnography requires a "postmodern skepticism regarding the generalization of knowledge claims" (Anderson, 2006, p. 373). Knowledge claims are investigated within the broader social context and also informed by the researcher's own experience, through a heightened sense of self-reflexivity, in this case, my experience as an informal caregiver. Analytic autoethnography is common in sociological research, as sociologists are often challenged to look for sociological involvement in their own lives (Anderson, 2006; Butz & Busio, 2009).

As “an opportunistic complete member researcher” (CMR) (Anderson, 2006), I was a member of the ‘community’ (a family caregiver) before I became a researcher, and thus will continue to be a member of the group when the research has concluded. As predicted by Butz and Besio (2009), I sometimes found it challenging to balance my role as a caregiver with that of a researcher. This process required a significant amount of reflection and debriefing after each interview and can potentially create “a deeper informative reciprocity between the researcher and other group members” (Anderson, 2006, p. 383). After each interview, I called either my advisor or my husband to debrief (without disclosing any confidential information) any feelings that I may be struggling with after hearing the stories of my participants.

Within 24 hours of each interview, I wrote memos detailing to myself the key takeaways from the interview, any disruptions that may have occurred (phone calls, visitors etc.), what the home looked like in terms of layout and medical technologies (particularly if pictures were not taken), and my own personal feelings about how the interview went. I took into account how I was feeling leading up to the interview (e.g. anxious, stressed) and assessed what could have gone better. Hook (2001) remarks that the researcher can be a grounding point in Foucauldian theorization therefore, my experience as a live-in caregiver was an asset to the data collection process by focusing on aspects that other non-community-member researchers may overlook.

Additionally, an essential component of this study is to understand how caregivers perceived medical technologies shaping their home and the changes that the home has undergone to transform from a private setting to a relatively public medical setting. Assessing the home space is essential, as Mong (2020) suggests, “opening a window to see inside multiple homes allows us to understand real needs, and gives us ideas about the policies needed to meet them” (p.91). Thus, following the interview, I asked participants if they were willing to show me

around their home, focusing on the areas where care is provided, and shared living spaces, and then also asked if I could take photographs. Observing the home space was a key part of understanding how (and if) the home has been adapted to receive care.

As a disclosure, I believe that all research is subjective. Numbers do not speak for themselves, people are not neutral, and our experiences shape each interaction that we have with one another. These interactions are often shaped by social scripts, which dictate how we respond, what we say, and what we choose not to disclose to others (Fries, 2009). With that in mind, I knew that to build rapport with caregivers, I would need to share my own experience with my participants. I wanted them to know that I was not (and am not) approaching this research as a means to an end. It is not a bump in the road to a PhD or a career in health care services. I am conducting this research from a position of experience and with the goal of helping future caregivers. Immediately following the demographic questions, before asking any questions on the interview guide, I shared my caregiving story with my participants. While I did not ask explicitly about what my role or experience had on the interview process, many caregivers acknowledged it.

For instance, at the start of the interview, Georgia was reserved and formal. She admitted later that she had cleaned her home prior to my arrival and seemed very aware that I would be a presence in her home. After sharing my experience, she relaxed and remarked, “thank you for explaining that to me, I really appreciate your being so open. Because there’s an understanding there, otherwise you wouldn’t really, fully know. There’d be sympathy, and empathy, and you know, kindness, but it’s not the same as living it.” May also agreed that until you have been a caregiver, you cannot anticipate what it is like. In response to reading the *Caregiver Recognition Act*, May observed,

> I don't know if the government has made a lot of effort, if I can be honest and say they made a lot of effort to understand what caregiving is about, though, I think to me it's like unless you've been a caregiver, unless you've been on that part and knowing what a caregiver really means, then it doesn't really like, I can't explain to someone everything that I do as a caregiver. Right, none of us can as caregivers, and no one will understand.

May went on to say that it is even more complicated to explain her situation to others, as there is nothing "medically wrong" with her mother aside from decreased mobility associated with aging. Although she is happy about her mother's good health, she says that people do not understand the extent to which caregiving still impacts every aspect of her life.

Katherine shared a great deal of frustration with other people's lack of understanding about the pervasiveness of caregiving. She states,

> Others don't understand it. Others your age don't understand it. That's the kicker. Especially as moms. They think, oh yeah, we're all busy. It's like, no seriously, you're not fricken busy. (laughs) I know you are busy, but this is a whole next level. That or if you have a disabled child or something then you could understand and you get it. Most people don't get it!

Katherine directed most of her frustration at her employer and mentioned a lack of empathy, particularly from male co-workers. She explains,

> Katherine: You know, I should really hate (workplace) for it. Because, looking back, like I say, how sexist can you be? The burden does fall on us. And the caregiving does. And I remember (boss) one day being, so very snarky. It's like, you asshole! I don't care if that's recorded! Like, he had a stay-at-home wife, right? Who could stay at home with the kids while he was working and building his career. I still remember that.
>
> Kaitlyn: There's very little empathy.
>
> Katherine: Yeah. From a male, (boss) when I had little kids, he knew, he knew what I'd gone through. They know, but they don't really care to get it. Like they don't understand the caregiving part.

There were several overlapping roles between me and Katherine, including being caregivers, mothers, women, and working in a similar field. These similarities resulted in a rapport that allowed for a very frank and honest discussion.

In other instances, some caregivers in this study revealed vulnerabilities to me that they may not have exhibited to others. Without a prior relationship, I do not think Martin would have agreed to share his caregiving struggles with any other researcher. As someone who adhered to traditional gender roles, I do not believe that Martin had shared his caregiving struggles with anyone at all, including his children. Kendra revealed to me the guilt that she feels over anticipating her dad's death. She does not want her children to worry about her, and continues to put on a façade to them that everything is alright, yet she is struggling deeply with feelings of resentment. Once the interview had concluded, Kendra thanked me for what felt like a "therapy session" and admitted that a weight had been lifted from her shoulders. She had not felt comfortable disclosing her ambiguous feelings about caregiving to others and had carried these emotions heavy on her heart for quite some time.

These deeply personal revelations highlight the emotional complexities of caregiving and the importance of creating a space where caregivers feel safe to share their experiences. Their willingness to open up to me as a peer, not just as a researcher, strengthened the trustworthiness of the research, and gathered information that a non-caregiver would not have obtained. In the next section, I describe the process of data analysis.

4.2 Data Analysis

Data, including interview transcripts and ethnographic field notes, were saved onto *Microsoft Word,* and then moved to *Nvivo 14* where they were organized into cases (keeping transcripts,

photos, field notes, additional information) together and coded. The coding process was multi-phased, iterative, and began as an open coding process (Clarke & Braun, 2016). Each transcript was read through without adding codes to re-immerse myself in the conversation. On the second read, I began to highlight and label codes that would become themes based on concepts I had identified in the literature (Clarke & Braun, 2016). Broadly, these concepts were "unequal power relations", "feelings of home", "medical tasks and technologies", "boundaries", "agency", and "surveillance". I also coded less theoretically-based phrases such as "experiences with home care", "medical errors", "types of support provided by caregiver/types of support provided by home care", "future suggestions", and "quotations that resonate." During the second read, I also made annotations about particular connections between caregivers, and provided background context in areas where the caregiver was referring to something that was not recorded.

Within the higher-level codes, I created more specific codes such as "ambiguity about the caregiving process," and codes which outlined the direction of surveillance and decision making, (to/from home care recipient, to/from home care worker, to/from family member, to/from medical professionals, to/from generalized others), which were indicated during a third read of each transcript. Finally, I also coded whether or not the direction of influence was perceived to be collaborative, assumed, accepted with reservation, or forced by the home care service, by the person receiving care, or by the family/friend caregiver. It was at this stage of the reflexive thematic coding process (Clarke & Braun, 2016) that I applied a Foucauldian analysis to the codes. These codes were used to inform evidence-based experiences of more theoretical concepts such as biopower, medical gaze, and professional discourses of medicalization. Within *Nvivo 14,* these codes were not reviewed externally, but my advisor read through a detailed explanation of the codes in an early dissertation draft.

Data, including interview transcripts and ethnographic field notes, were analyzed using reflexive thematic coding (Clarke & Braun, 2016) and then analyzed with Foucauldian theorization (Khan & MacEachen, 2021). Particular attention was paid to the experience of informal caregivers, while also focusing on a "regime of practices" (Brady, 2014) that impacts their caring. This involves interrogating the 'conduct of conduct' (the approach to governance that is based on understanding our intrinsic nature) and can be uncovered by looking for what is made visible by the participant, discursive ways of thinking and acting, and how participants portray themselves (Brady, 2014, p. 23). As summarized by Schirato, Danaher and Webb (2012), "Foucault's work makes visible the elements and forces through which power operates in institutional space" (p. 51). Although the home is a private space, the introduction of home care services into it by default makes it a public space that is restructured to mirror aspects of the institutional space of a medical building such as a hospital. This research is essential to making visible the often-overlooked home space through a Foucauldian lens to understand how power operates and how the gaze is extended, therefore, particular attention was paid to contradictions within the interview, and what the participant chooses not to disclose.

Although there is no one way to conduct it (Hook, 2001), Foucauldian analysis is particularly concerned with understanding "how the construction of 'meaning' is connected to the power imbalance in our society" (Kahn & MacEachen, 2021, p. 1). Foucauldian analysis does not use pre-established meanings but allows the participants to construct their own definitions based on their worldviews and experiences. Thus, codes were also created for definition-based questions, such as 'what does family mean to you'. In other words, the words that we use to describe or explain certain phenomena soon become how we come to understand that phenomenon. For example, if live-in participants describe their home or caregiving

experience using medical terminology then, through the use of language, their home becomes medicalized. Similarly, if live-in caregivers begin to refer to themselves using medical terminology, the people for whom they provide care may begin to interact with them as medical professionals and not necessarily friends or family members.

When applying a Foucauldian approach, what *is not* said is just as analytically important as what *is* said, therefore, the researcher must take an interpretive and critical approach to data analysis (Bryman, 2004). As discussed previously, this study does not aim to be neutral in its collection or analysis of data. As suggested by Schirato, Danaher and Webb (2012), "discourse does not merely refer to the content of communication, but the ways in which communication, ideas and other sequences and signs are exchanged and signified" (p.34). Further discourse is used to determine *why* something is true or false and how it got to be there. As such, Foucauldian approaches look for differences and multiple sources of power and legitimation within a particular social context rather than something that is similar, familiar, and universal (Kahn & MacEachen, 2021). Therefore, I did not merely investigate how caregivers and their home spaces are medicalized, but how they came to be medicalized, the flow of power, and how they participate in the process of medicalization, which extends the medicalized space and gaze (Foucault, 1975). My methodology focuses on understanding how the physical construction of the home as a site of home care provision shapes subjectivity. How has the home care experience affected how carers think about themselves and their homes? And, how might these particular configurations of subjectivity align with and reflect broader social discourses, such as, for example, neoliberalism?

Manitoba was an ideal research setting because it is regarded as having "the most established and comprehensive universal homecare program in Canada" (Keefe, 2011, p. 15), and is the only province with legislation to recognize the importance of informal caregivers (The Caregiver Recognition Act, 2011). Further, Manitoba is the only province that has a policy indicating that all care recipients must have a stable backup plan in place (Toews, 2016), thus informal caregivers are integral to the delivery of home care services.

The following chapter describes the experience of being a caregiver from the perspective of Manitoba caregivers. Where appropriate, the quotes, stories, and vignettes are supplemented with photos from the caregivers' home tours. The honesty and forthcomingness of these participants to share their stories with another caregiver adds a layer of trustworthiness to this analysis. I believe what these caregivers shared with me has been expressed to the best of their abilities, and it is with gratitude that I analyzed, and will now share their stories.

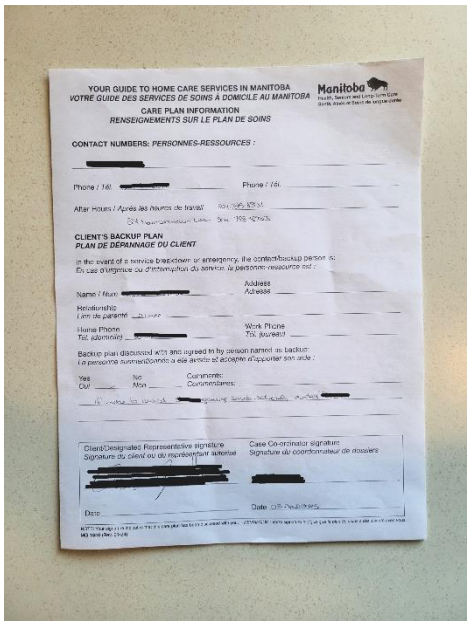
YOUR GUIDE TO HOME CARE SERVICES IN MANITOBA
VOTRE GUIDE DES SERVICES DE SOINS À DOMICILE AU MANITOBA
Manitoba
CARE PLAN INFORMATION
RENSEIGNEMENTS SUR LE PLAN DE SOINS
CONTACT NUMBERS: PERSONNES-RESSOURCES :
CLIENT'S BACKUP PLAN
PLAN DE DÉPANNAGE DU CLIENT
Name / Nom:
Address
Adresse
Relationship
Lien de parenté
Home Phone
Tél. (domicile)
Work Phone
Tél. (travail)
Yes
Oui
No
Non
Comments:
Commentaires:
Client/Designated Representative signature
Signature du client ou du représentant attitré
Case Co-ordinator signature
Signature du coordonnateur de dossiers
Date:

Figure 1: Backup plan contract

Chapter 5: Analysis of Findings

The interview data is organized into the following themes: what ‘home’ means to caregivers, modifying home, medical tasks and technologies, medical errors, what ‘family’ means to caregivers, identity changes, and decision-making and collaboration. The words and experiences of the participants will be supplemented with photographs from home tours.

5.1 What ‘’Family’ means to Caregivers: “It really isn’t in your benefit to pick a fight with the family”

In all but one case, caregivers in this study were related to the person they were caring for by either blood or marriage. Johnathon, however, was caring for a friend, Harold, who he first met through the agency he worked for. The following section describes the caregivers’ definitions of ‘family’; this is relevant as their definition may have impacted their decision to live with and care for their loved one, and in turn, may have changed since introducing home care workers into their lives. As informal caregiving intersects with formal health care systems, personal relationships are reshaped by medical frameworks and institutional norms.

Johnathon was asked to open his home to an older adult by his work, an agency that provides care for people living under the guardianship of the state. Johnathon feels he has an obligation to care for the recipient of care who lives with him, despite them not being related, for two reasons, both pressure from his employer and a socialized responsibility to help others. He explains, “with the agency you just kind of feel like you have to…I agree to say that somebody pressure[d] me into it, but I still feel like if I have a home and somebody needs a home…. I felt like it was my duty to help.” Johnathon goes on to elaborate that his ‘duty’ also originates from his faith, his cultural upbringing, and the sense of connection he feels to Harold, who is a fellow

immigrant. Johnathon recognizes that their relationship has deepened over the years because of their co-residence, and that he and Harold regard one another as family. Despite Harold being significantly older than Johnathon, Harold will buy Johnathon a Father's Day card each year, "and he [Harold] will say 'thank you for being there for me', and that really touches me [Johnathon]".

Throughout the interview, Johnathon expressed frustration with the agency he works for due to a lack of physical and monetary support. It is important to note that Johnathon does not provide care as part of his job description, and is not a formal care provider, but does receive a stipend from the agency to cover the costs of having Harold in his home. He repeatedly emphasized that he does not provide care because of the money, and that the monetary stipend is so low that he actually pays out of pocket to keep Harold in his home. Thus, Johnathon recognized that he was burning out and debated letting the agency "come and get him", or in other words, he could not continue providing care for Harold. Upon further reflection, he determined he would not be able to "give him up", and even when it becomes medically necessary that Harold is "no longer able to live with [him], it will be terrible. Like, we've been building such a bond that it's going to be hard." Whenever possible, Johnathon brings Harold to his family gatherings, and his extended family refers to Harold as family, too.

For those who are related to their care recipients through blood or marriage, many provided an all-encompassing definition of family. For example, Kendra states that "family is pretty much everything." She elaborates that she does not know what she would do without her children, speaks with her ex-husband on the phone daily, and visits her Dad multiple times a day. Kendra rearranged her entire life to provide care for her family members and has made the decision not to 'put herself first' until her father passes away. Martha also stated that family is

"home and a place of love," while also acknowledging that this can sometimes come fraught with complex emotions. Katherine tried to define family in terms of blood relations but struggled to identify those whom she felt close to. She defined herself as an "only child," although she had a brother who died when she was a teenager and has half-siblings as well. Throughout the course of the interview, Katherine maintained that her children and husband were her main sources of love and support. Amanda also defined family through blood relations, saying that she was an only child, yet always included close friends in her circle of 'family'.

Rachel emphasized that family involves an "element of care…in [her] perspective, I guess that family is sort of the people you rely on and who just do the things that you need." Martin echoes this response by briefly stating his family "comes and helps [him] out" with practical matters. Relying less on physical tasks and more on social support, Maddison felt that family are the people "you can always go and talk to, like they're not going to leave you and stuff." She later surmised that living with her grandmother at such a young age likely made her and her siblings closer to one another, as they were often left independently to their own devices. Joanne had a very protective element in her definition of family, placing herself as the protector against others, particularly home care workers. She argues that no one knows her mother as well as she does and "it's not to [home care's] benefit to pick a fight with me. Like, with the family. It really isn't to your benefit to pick a fight with the family. And I am not going to take any more of this stuff [bullying by home care staff]." Divorced and without children, Joanne says she needs to fight for the only family member she has left.

Similar to Johnathon, May emphasized cultural heritage as central to her definition of family. As an immigrant of Asian descent, May highlighted the importance of a family's ability to understand one another. Because her family felt different from other Canadians, it was

essential for them to remain connected to one another. May also acknowledge her perceived difference between Western and Asian cultures' understandings of familial responsibility. She explained that Asian families see nursing homes as a “last resort”, and it would be “rude” to even consider them for a parent. This innate understanding comes from a duty of reciprocity. She states, “[mom] was always very good to us before when we're younger. Took care of us. So, kind of like it's our turn in a way. If you could look at it that way, you know? And I'm not gonna say, I didn't make any sacrifices or whatever, but that's what I have to do right now, I think.” May’s brother is also a live-in caregiver for their mother’s sister, and she acknowledged that both her and her brother are repaying the care that was given to them. They often joke about which of the sisters is “worse,” and neither wants to trade with the other (May’s aunt has severe dementia, but no physical ailments, while May’s mother is the opposite). It is also important to note that, until May’s older brother signed up with home care first and then suggested it to May, that she considered it for her own mother. This again highlights the importance of the opinion of others in Asian cultures.

The concept of family was also a difficult subject for some caregivers. When asked directly about family, Georgia only replied that she “does not have a lot of family in Canada” and did not elaborate. In contrast, Tammy remarked on the complicated nature of multiple family relationships. She states, “that's a hard one. I have three sisters and three brothers and three of my sisters have not spoken to my mom in 10 years for whatever reason, so my family is my mom and my brother. That's my family, and I wouldn't change anything in the world for. Mind you, he can be an asshat too, but we still love him." This complex relationship with her sisters prompted Tammy to install a camera in her living room because she was concerned her siblings were stealing from her. This has been a point of contention for the home care workers, as formalized

surveillance of the workers is not allowed by home care. Additionally, because the relationship between her sisters and mother fractured, Tammy feels she and her brother are the only ones capable and kind enough to care for their mother.

Pamela also acknowledged the more ambiguous nature of family relationships. She began by saying her adult children have moved away from the city and are living their own lives, which she described half-heartedly as "cool." Pamela noted the feelings of loss that her husband was experiencing because he could no longer travel to see his children. Also discussed by Pamela was the changing nature of family relationships since her husband's diagnosis. From her perspective, Pamela's extended family members now view her husband only in terms of his medical condition and deficits and not as someone who is capable. Pamela's husband has a neurological condition which impacts his physical body, particularly his speech, but his cognitive abilities remain intact. She recalled a recent extended family gathering where it was made apparent who was comfortable interacting with her husband, and who could not be bothered to put in the extra effort. She explains,

> …other people's comfort level with people with disabilities, you get to know more about it. We had this family gathering yesterday. There's probably 25 people. But it's very interesting to see who gravitates to [husband], knowing that it's difficult to understand him. He's unsteady, he can't do things, and some people just, I don't really know, don't want to do that. And so they keep their distance, whereas my nephew was there and he just plops himself right down beside [husband] and holds the plate. Yeah, he's great. I don't blame them. I probably might do the same. I feel more badly for him…And once somebody starts talking to them, they realize, cognitively, he's with it, if you can understand him.

Pamela adds that the hesitancy of others to engage with her husband is isolating for both of them but argues that many people have not had the experience of being a caregiver, and therefore do not understand the strain it can put on relationships. Thus, while her husband is viewed in terms of his medical condition, Pamela is viewed now only as his caregiver.

What is clear from the caregivers' definitions of families is that they all recognize the importance of other people in their lives. For some, family is all-encompassing, while for others it is transactional in nature. As I was coding the transcripts, I sometimes found it hard to decipher clearly which was the caregiver's definition of family, and which was their definition of home because they were so closely intertwined. As will be evident in the following section, without 'family', whatever that definition may be, there is no 'home'.

5.2 What 'Home' means to Caregivers: "We've been married 63 years"

In order to understand how a home might become medicalized, it is essential to understand what 'home' actually means to the caregivers and how this definition may change throughout the caregiving process. Aligning with Foucauldian theorization, it was important as a researcher that I did not impose my own definition of 'home' on the caregivers I interviewed (Kahn & MacEachen, 2021). Thus, as part of the interview guide, I asked each caregiver what 'home' meant to them. Response was often followed by a long pause, and some caregivers remarked what a great question it was. A common, although not universal, theme among participants was that home is a place of family, love, safety, and privacy.

In Katherine's words,

> [home] could be all sorts of things. Somewhere you feel like you've got some privacy. It's a big part of it. Privacy and uhm, sense of being all yours…. Where you are safe, and comfortable, and honestly, to be really home, I need to have the kids around to have a family around. Including extended family…I tell my kids, this is always home. I know you'll be leaving, but, it's somewhere people are always welcome to come back to. I would never, no matter how big disagreements and arguments get and everything, I would never, I don't turn anybody away.

Katherine's remark not to turn anyone away is part of the reason why she decided to have her mother move in with her. Several members of Katherine's family have a long history of mental

disorders, including her mother. Despite the challenges she knew this might eventually cause, particularly while raising a young family, she did not want her mother to live anywhere else.

Joanne, Johnathon and Amanda all expressed the need for home to be a safe and private space. Johnathon states that "home is where there is a lot of love, a lot of laughter, there's sorrows as well…. home is joyful. Home is a place of peace and safety." Amanda noted that she is "an introvert, [she] really thinks of [home] like a quiet space to get away from people." Her quiet space was intruded upon by inconsistent home care workers, which she felt was overwhelming and chaotic. She was relieved when they were able to build her father his own private suite in the basement, which minimized her interactions with the home care workers and restored some peace for her.

Through an accumulation of negative experiences with home care, Joanne also felt that the privacy of her home had been violated. At the time of the interview, she was in the middle of a formal appeal to the Home Care Appeals Office due to a Personal Health Information Act (PHIA) breach by one of the workers that had been in her home. To rectify the situation, the case coordinator felt it was necessary to meet with Joanne, a team manager, and several other home care providers. The suggested meeting place was Joanne's home. Joanne felt that this was a "numbers game" whereby home care was trying to intimidate her in her own home, and thus, she refused to host the meeting. She elaborates,

> the taking of the politics into the home is also the way. Like, it invaded my emotions. Like, her privacy was breached. Like, your home is your safe space. And oh, well 5 people are going to come into your house! NO THEY'RE NOT! This is a safe space, and you people have violated it. All of you are responsible for this.

Joanne concluded our interview by saying that she no longer feels safe in her own home because of the bullying tactics used by home care, and is worried about the safety of her mother due to

home care visit disruptions. Joanne's resistance to host the meeting demonstrates her agency and ability to exert control over her home environment, however, she admits she will have to host the meeting at some point to resolve the issues and ensure her mother receives consistent care services. Ultimately, it is her concern for her mother's well-being that for will force Joanne to 'go along with' what home care wants her to do, highlighting the complex flow of power relations between and amongst caregivers. Joanne's experiences of intimidation and bullying by home care workers will be further discussed in a later part of this chapter.

Pamela and Kendra mentioned that 'home' included a sense of ownership and belonging. Living in her late mother's apartment, Kendra was not living in her own home, which negatively impacted her self-esteem. She emotionally remarked, "I mean, I love it. My mom is here (laughs-points to urn). So, everything here...is hers. It's not mine. It's not my place. You know, I'm just sort of (starts to get emotional), a 70-year-old that's going nowhere." In Western society, purchasing a home is often viewed as a major milestone of adulthood and not living in her own home was perceived as a failure in Kendra's eyes. For Pamela, she highlighted the need to "engineer [her] environment to the way that's comfortable for [her]. And it supports kind of what [she] want to be doing on a day-to-day basis". She continues to say that privacy and "having [her] own space" are important to her, as she and her husband used to live very independent lives from one another. This is something that continues to bother Pamela, as she feels more housebound than she ever was before. She expressed a desire to travel and visit her children but knows this is not possible while her husband is still alive, thus she feels 'stuck' in her home as a caregiver.

Rachel and May both remarked on the function of their home taking precedence over the perceived state of the home. May emphasized that "home means that people in the home get

along with each other. There's warmth in the home. It doesn't matter if it's like a fancy home. There's obviously I don't live in a fancy home right now because my mom doesn't want to ever move anywhere." This interview was conducted via Zoom, and it was not 'obvious' to me that May's home was not 'fancy'. Raising this point in the interview suggests that May might prefer to live somewhere fancier if she were not living with her mother. Rachel had a more practical impression of 'home' in the sense that home is "where you do your living, where you spend most of your time, and where you're comfortable." Rachel's response may be indicative of the many homes she has lived in over the course of her life.

Maddison, who had recently moved out on her own, replied that home was not a physical space, but home is "wherever my family is," while Martha remarked that home means "family and a place of love." Georgia echoes these comments saying that "home is identity." Georgia sheepishly added that before I arrived for the interview, she cleaned her home and moved her exercise bike out of the living room and tucked it into a spare bedroom. She wondered aloud 'why she did that', however, this type of identity work has been identified among caregivers and care recipients alike, as they try to present the best version of themselves (Kuryk et al., 2023). Because Georgia feels home is identity, it makes sense that she would also try to present to me the best version of her home as well.

I was surprised in some cases how sensitive the question of 'home' could be for some of the caregivers. In particular, Tammy and Martin both were visibly emotional in their response. Tammy replied, "don't get me emotional. [Home is] having my mom here." Tammy's household appeared to be one where yelling, arguing, and poking fun at members of the household is a normal form of communication, thus I was surprised to hear how deeply important living with her mother was to her. I was also taken aback by Martin's response. Having known Martin for

most of my life, he always appeared to me as a very large, loud, and stoic man. I was slightly scared of him as a child because he was missing several fingers due to work accidents. When I asked him what home meant, he simply replied, “we’ve been married 63 years,” referring to the time he has spent with his wife. His response is one that is sometimes neglected in conversations when researchers and service providers discuss ‘home’ in the tangible sense. What Martin and Tammy eloquently highlight is the importance of considering relationships, family, and emotional ties when we enter someone’s space.

For these participants, home is not just bricks and mortar or a place to be assessed for risks and modified for safety. Home is a feeling, home is a relationship, and home really is where the heart is. What this section has highlighted is the ‘relational’ aspects of home, and what is notably absent are elements that are often associated with institutions, such as routines, schedules, and risks. The following sections will explore how suggestions from home care professionals challenged caregivers’ perceptions of home, focusing on the physical modifications made to the home and the relational shifts that occurred with the introduction of formal home care services.

5.3 Modifying Home: The “Madhouse”

While “Aging in Place” continues to be the goal of governmental policies and programs and the sentiment of the general public regarding planning for the later stages of life (Dalmer, 2019), it is important to acknowledge that changes will need to be made to that ‘place’ in order for the person to remain there. This might seem straightforward, as many people picture older adults with reading glasses, hearing aids, and walkers, yet changes to one’s private sphere are often

invisible to the general public and are not considered until they are needed in one's own home. This section describes the wide range of accommodations that were made (or not made) by live-in family caregivers to ensure their loved one could remain at home. As will be described, some of these changes are relatively minor, while others involve major renovations or complete relocation. The following section will also assess who suggested the accommodations and for what purpose (risk management, worker safety, etc.), as well as what changes were *not* made, and why. Finally, this section will conclude with a summary of *how* these changes impacted the family caregiver and their orientation towards their home space.



Figure 2: Martin's living room, with an off-centre table to protect his wife from injury

To varying extents, nearly every caregiver (11/13) that was interviewed for this study had to make some kind of adaptation to their home to allow their loved one to live there safely and comfortably. These changes were most often made in the bathroom and bedroom. For May in particular, it was the inaccessibility of the home, "older homes, older stairs, and because it's her mobility that started to slow down a little bit," that prompted the need for home care to ensure her mother was moving through the home safely. Even if a major modification was not needed, participants sometimes described various reorganization of previous spaces. For example, Martin pointed out to me that the living room table was off-centre from the window because a few months back, his wife had fallen and hit her head on the corner. In a house that was immaculately kept, it was clear that an off-centre table was a point of embarrassment for Martin,

and a reminder of his wife's fragile mobility. It is through this subtle furniture rearrangement that Martin is reminded that his home is now a place of 'risk'. Martin also had made adaptations to his bathroom (raised toilet seat, shower bars), and his wife's walker was kept in the dining room when she was not using it. Martin and his wife no longer eat in the dining room, and thus, it was used to keep the walker out of site.

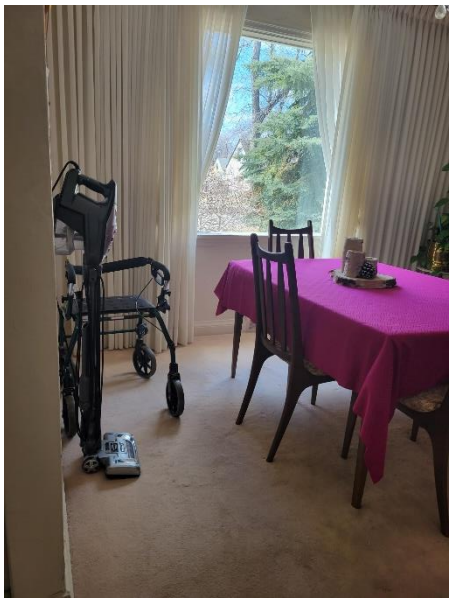

Figure 3: Martin's wife's walker hidden away in the dining room

Another example of changes to the home without physical imposition comes from Maddison and Katherine, who were caring for the same older adult. The home did not require major changes for home care to provide services, however, due to their mother and grandmother's limited mobility, she could not go up the stairs. This meant that the only bathroom on the main floor of the house was reserved for their mother/grandmother and the home care workers. Maddison lived with her grandmother when she was a young child and she distinctly remembers, "how dirty it [the bathroom] was. I think that was the main thing. Even when you're 9 and it smells like pee everywhere, it's just like, that's the one thing I remember." The issue of smell in the home was brought up by Maddison on several occasions during the interview, where she remarked,

> I remember because she had a room on the main floor and like, the most distinct thing I could remember is how badly it always smelled. It's kind of gross, but it always smelled like pee and stuff because I think she wasn't very capable of cleaning. So that's one thing that I always remember. I just remember how bad that area, like the washroom and room area smelled. And home care could never like, properly clean it.

She also noted that she was advised by her parents to "stay away" from that bathroom because it was so dirty. Because Maddison was so young when she was living with her grandmother, she

said that she was not embarrassed by the smell at the time, but if she was providing care now and having friends over, it would likely cause her embarrassment. Katherine also recalled the distinct smell of urine on the main floor. Although her family physically had space for her mom on the main floor, the smell of urine and soiled laundry often wafted through the house, and Katherine worried regularly about the mixture of soiled laundry and baby clothes in the washing machine. It is in these instances where the formalized task of laundry for the home care worker intersected with the private housekeeping task of personal (baby) laundry by a family member, thus blurring the boundaries of home and workplace. Although no physical adaptations were made to the home, the noticeable smell remains a defining memory of the caregiving experience for both Maddison and Katherine.



Figure 4: Pamela's husband's bedroom

Pamela also has not made major adaptations to her home, but during the home tour, she revealed to me that she and her husband have been sleeping in different bedrooms for about two years. Due to his medical condition, posterior supranuclear palsy (PSP), Pamela was finding it hard to sleep at night, and it was decided that her husband would move into the guest bedroom. His bedroom was equipped with a hospital bed, handrails, a commode, and a nightstand containing his pills and other medical supplies. Despite having a commode in his

bedroom, their shared bathroom also has grab bars on the toilet seat. It is an important consideration that Pamela did not bring up separate bedrooms in our initial interview. This omission may indicate the normalization of adaptations in her home, reflecting an internalization of her home as a medicalized site. It is no longer something 'novel' to be discussed, but simply something that has been done to ensure her husband can receive care, and she can get a restful sleep.



Figure 5: Raised toilet seat with grab bars in Pamela's bathroom

The bathroom was a common site for medical adaptations and technologies for participants in this study; indeed, this is most commonly cited by occupational therapists as a site of high risk (Canadian Association of Occupational Therapists, 2011). Rachel and Tammy both recall grab bars, a raised toilet seat, and a shower seat in their respective mother's bathrooms. Kendra installed a raised toilet seat for her stepfather to prevent him from falling. In these cases, their homes were assessed by an occupational therapist who recommended the technologies. Pamela also had grab bars and a raised toilet seat in her bathroom, but she installed those for herself following knee surgeries. Pamela is a retired occupational therapist and knew herself that these accommodations would be helpful. Additionally, Joanne stated that there was tension between her and the case coordinator because "I had shower doors on my bathroom and neither my mom or I like curtains. We are definitely door people." The case coordinator felt that this was hindering the quality of care that could be provided, but Joanne was adamant about leaving the shower doors in place.

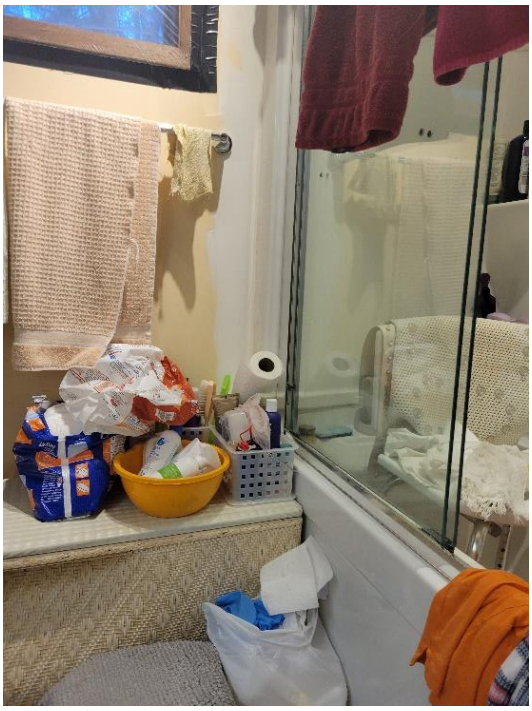

Figure 6: Joanne's shower doors - vehemently does not want a curtain despite home care's suggestion

In the cases of Martin and Joanne, medical adaptations like grab bars and toilet seats were not the only changes made to their bathrooms once home care started. Martin and Joanne both felt it necessary to write, print, and hang signage in their bathrooms to communicate with the home care workers. Joanne often needed to assist home care workers when her mother needed to use the toilet, thus she would frequently supervise their work. She noticed that the workers were making a mess and leaving the toilet lid up when flushing, something that she felt was unsanitary. Joanne elaborates that she felt the workers were disrespecting her space. She explains,

> you'll see in my bathroom, I have signs, like, (sighs) I mean, were you born in a sty? (laughs) I give them instructions about how the household works and they don't listen. I mean, it's the same people. And I understand that they go to many places. But I mean, it's a home! If you want to work in an institution and have all the cleanliness and the standards of the institution, you go work there! But if you are coming into a home, you are just, this is a home! It's still a home! And you are providing a service. And I get that you have some safety things, but, you are still providing a service. You are not in control of the home, and you are not in rule of the home….



Figure 7: Joanne's directions in the bathroom to the home care workers

> I had to put up a sign that that says, please shut the cover when you flush the toilet…And, it's like, if you are going to mess it up, you are going to clean it up. And it's the same thing, it's like you're walking and stuff is thrown all over the place, they don't, it's not an institution and somebody is coming by every 6 hours and going through and cleaning all the, and sanitizing. When you leave the toilet seat up, it goes all over the place. And spraying, peri-care (makes splashing noises) all over the mirror looks awful. Like, could you have some consciousness of, you know, that you're in someone's home and I don't have a janitor come. I'm not saying that you should clean up everything, but just have a little bit of awareness, a preventative awareness. Or, you know, sort of just be cautious that you are in someone's home. Be respectful of their rules and their way of doing things. I am not asking them to clean my house. But you can shut the toilet! But I had to put a sign up. This is where my mother's towels. These are my towels. This is the communal towel. Like, I feel like I have to put signage up. I mean, the title of your study is medicalizing your home. And this is medicalization.



Figure 8: Another sign in Joanne's bathroom with instructions to home care workers

Joanne felt the need to put up signs to retaliate against the 'tools' of the home care staff. She felt that if she continued to verbally and directly communicate with the home care workers that it would reinforce her reputation as a 'difficult' caregiver. Thus, she hoped the signs would serve as a subtle, yet constant, reminder to the workers that she was still in control of the space.

Martin also felt the need to put signs in his bathroom. On one occasion, he observed the home care worker brushing his wife's teeth while she was sitting on the toilet. He thought it was unsanitary, and due to the layout of the bathroom, could not understand how his wife would spit and rinse her mouth in the sink, which was adjacent to the toilet. After seeing this, Martin lost trust in the morning workers, who he felt were trying to take "shortcuts" to end their shifts early. This prompted him to write and tape a sign on the cabinets above the toilet in the bathroom

reminding the workers of all the steps that are included in his wife's morning routine. The list reads:



Figure 9: Martin's handwritten instructions for home care workers in the bathroom

[wife's] morning care:

- Toilet her first thing AM
- Will need direction & assistance with this and let her sit for 3-5 minutes
- Fresh panties/pads. Wipes on toilet
- Brush teeth- toothbrush on shel(f) above sink
- Wash face
- Com(b) hair – brush on shel(f) above sink
- Clothes on chair in bedroom

Despite these tasks being listed on the task sheet provided to workers by the home care agency, Martin did not feel this was sufficient in preventing "shortcuts." He added that he did not want the workers to feel like he was 'watching' them, and so the signage was a passive solution to ensuring his wife received quality care.

In addition to bars in the bathroom, a raised toilet seat, and a shower seat, Rachel recalls that a Hoyer lift was installed in her parents' bedroom, but that it "was for the health care workers and we just hoisted her up…she only weighed like 85 pounds so it was easy enough to just carry her around." When caring for her mother became too much, Rachel's mom was paneled to a long-term care home, however, she was still able to come home on weekends. Despite most of the care being transferred to the institution, Rachel said they "were still heavily involved" in her care on these weekends and had to leave the medical technologies in place.

Johnathon was in a particularly unique situation because he was providing care through an agency for someone to whom he was not related. The agency required additional safety measures and documentation of these measures to ensure the care recipient was living in a safe environment. This greatly annoyed Johnathon, who felt these safety measures made his home look like an institution. For example, framed on the wall, Johnathon needed to have an "escape route" plan in case of a fire or other emergency. Additionally, he needed to have a fire extinguisher displayed on each floor of the home. While he would normally keep a fire extinguisher in the house, he did not like that it was always visible to those who came over. He felt that this "intrusion…changed the physical environment of the home." He goes on to say, "we try our best not to make it to look institutional, but in a sense, it looks institutional because that's what the agency requires us [do to]." Johnathon also noted that he could not have friends and family stay the night in his home if these guests were not pre-approved by the agency. He felt this was prohibitive to the welcoming environment that he wanted to create in his home and contradicted the cultural "open door" values by which he was raised.



Figure 11: Fire extinguisher and emergency escape route in Johnathon's home



Figure 10: Another fire extinguisher on a different floor of Johnathon's home

Medical alterations were also made outside of the caregivers' homes. For example, Rachel's father installed a ramp outside of their home so her mother could come home from an institution on weekends. In contrast, Martha does not have a ramp or wheelchair lift installed outside of her home, although it was suggested to her by multiple physio and occupational therapists. Instead, to accommodate their requests, she installed railings on the side of the stairs for her mother to hold on to, solar lights along the front walkway, and rubber mats to prevent falls. I asked Martha the reasoning for not wanting to install a wheelchair lift, and she noted the reasoning was two-fold. First, her mother had lived in her home for 60 years and did not want "something" (presumably something that indicates dependence) outside her house. Secondly, she stated, "she [her mother] doesn't want to spend the money and she says I'm not going to be here long enough to make it worthwhile to put in." Martha's mother also had the same reasoning for rejecting the suggestion of the case coordinator to install a Hoyer lift in the bedroom. Although this would make transferring easier, Martha agreed that tearing up an older home like theirs would be too expensive and would change the layout of the whole house.



Figure 12: Rubber mats and solar lighting outside of Martha's home

Martha also resisted the suggestion from her mother's case coordinator that a commode be placed in the living room. The case coordinator commented that the home care workers, particularly one-time-only workers, were struggling to get Martha's mother to the bathroom in a timely manner because they had to help her from her chair in the living room, and walk with a walker to the bathroom, and then come back to the living room. This journey was putting the



Figure 13: A commode in Martha's mothers bedroom

workers behind schedule, and to speed up the process, the case coordinator suggested that a commode be placed in the living room, and the workers could more quickly dispose of the waste without Martha's mom having to get up and walk. Martha was horrified at this suggestion and how it could impact her son, she explains,

> I got a kid here. A 17 year old boy. Do you think he wants to see that or should see that? And I said he's not even a normal boy. He's on the autistic spectrum. They don't look at the family dynamics, right? Or they don't want to.

As a compromise, Martha agreed to have a commode in her mother's room instead of the living room to help with the timing of morning and evening calls, or in the afternoon if her mother is having a nap.

In contrast to Martha, Georgia did make adjustments that impacted the whole house. For Georgia, grab bars in the bathroom were the first change of many, and indicated the start of her husband's physical decline. She states, "we started doing things like a lot of grab bars. You know, after the horse got out of the barn, the railings going down up all those little things, then we put a railing on the side of his bed." After a series of medical errors in a Winnipeg hospital, Georgia felt her husband would be better cared for at home. To do this, "[the] library was decked out, made into a hospital room…we had a hospital bed, commode, everything." Georgia described this time as living in a "madhouse" because of the workers that were coming and going all day long, and the emergent needs of her husband at night. She recalled that they had been sleeping in separate bedrooms for several years, because he wanted to avoid waking her up at

night when he was more mobile, but when the hospital room was built, she "put mattresses on the floor, on both sides of the bed and was lying there with him as much as [she] could." When Georgia's husband passed away, she immediately emptied the hospital room but has not restored it as a library. I asked if the cleaning process was helpful to her healing and grief to which she replied, "you know, you can't remove when caregiving ends. There are so many reminders. You cannot. They're everywhere." Georgia hopes that the experience of caregivers 'post-caregiving' could be studied in more depth by other researchers in the future.

In two instances, caregivers had to uproot their lives and by extension, their homes, to accommodate the needs of their loved ones. Kendra and Amanda were both caregivers for their father/father figure and decided to live with their loved one rather than provide care from afar. Amanda's father was living across the country when he experienced a medical emergency that left him with severe physical impairments. Before this, Amanda's father was living independently and it came as a shock to the whole family that following his four-month stay in the Intensive Care Unit, he would be unable to return to his home. Thus, Amanda and her husband decided that it was best to sell her father's home and move him across the country to live with them. She explains,

> we lived in a small house (laughs) at that time. So, we ended up setting him [her father] up a temporary bedroom, like our mud room. So, it was a 2-bedroom house, you know, me and my partner and my daughter already had our bedrooms and then we started frantically looking for another house. I was still in school at the time so everything had to be on my partners' income only. So, we ended up finding a house that like, works-ish. We were able to renovate the basement into a semi-independent suite. Uhm, and he lives there.

Later in the interview, Amanda clarified that while they were renovating the new house, her father was accessing Priority Home Care Services.[9] Because of the regular interactions with occupational therapists, the renovation of the new home was done to ensure it would be accessible for her father. She elaborates,

> [OT] came and helped us figure out what adaptations we would want to make for his suite. So, you know, we changed the bathtub to like a low bathtub. We did stuff like that. We were concerned about whether he could be in our basement or if we should use part of the main floor. Uhm, but they [OT] were actually really happy to have him in the basement because he had enough mobility that he could go up and down the stairs as long as he has a walker at each end.

She added that the OT expressed that having her father in the basement would encourage him to be active by going up and down the stairs. Amanda agreed that this was the best place for her father because it also preserved her own privacy (central to her sense of home) and her father's sense of independence. Amanda later mentioned that because she often works from home, having her father on a separate floor of the house is a way to spatially distance herself from caregiving.

Kendra had a very different experience as a live-in caregiver. Until I arrived at her home, I did not realize that she 'technically' does not live with her loved one who receives home care but lives in the same building as her ex-stepfather. Several years ago, Kendra's mother fell ill, and Kendra decided it would be best to sell her home and move into her mother's apartment with her. Coincidentally, this

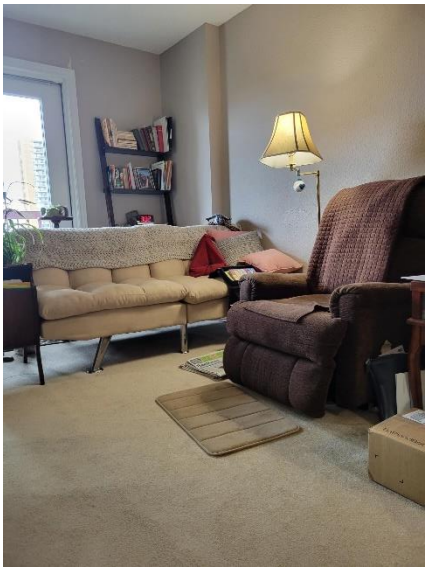

Figure 14: Kendra's late mother's living room

[9] Priority Home is an intensive 8-week home care program that focuses on rehabilitation. In addition to regularly provided home care services, Prime offers regular (sometimes daily) interactions with occupational and physiotherapists.

apartment building is also where Kendra's ex-stepfather was living. After two long years of caregiving, Kendra's mother passed away, and around the same time, her ex-stepfather, whom she affectionately called "Dad," also fell ill. She then decided to continue living in her late mother's apartment so she could provide care for her dad. Thus, Kendra did not make physical changes to her home, but instead moved into a new home that was not her own, and continues to live in a space that is not "hers." Without additional family support, Kendra feels obligated to provide care for her father until he passes, knowing that the end is coming very quickly. When I asked her about living in a space that is not her own, she took a deep breath and replied, "...this is an okay place. I would like some place that is bright. It is so dark in here, it gets me depressed at times. Yes, I would just like to have (sighs) my own apartment. Get my own furniture, light, bright, plants, airy." Finally, when I asked Kendra if I could take pictures of things she felt were medical in her home, she told me to take pictures of everything, because nothing in the apartment was hers and everything reminded her of her mom, her mom's medical condition, and her dad's declining health.

Regardless of the degree of adaptation, the caregivers in this study expressed that the changes made to their homes served as a constant reminder of their caregiving role. For some, adapting the home was the first 'official' sign of decline for the health of their loved ones. Most often, these changes were suggested by workers in the health care system, and if they were refused, were met with some level of pushback. However, modifying the home to provide care is not the end of the medicalization story, but simply the beginning. As will be discussed in the next section, caregivers not only had to standardize their living spaces at the request of the public system, but they had to provide medical care using medical technologies.

5.4 Medical Tasks and Technologies: “I nursed him back to health”

Regardless of the amount of care that a care recipient received or the severity of their diagnosis, every caregiver in this study performed what they considered to be medical tasks, and more often than not, the tasks were done without what they saw as adequate training. These tasks were sometimes expected of the caregiver to be integrated into other aspects of caregiving, or in other words, just added to the list of tasks they were already doing on a daily basis. In other cases, these medical tasks were performed because a trained and skilled worker failed to show up for their shift in a timely manner, or at all.

For instance, while Johnathon does not regularly provide medical care for Harold, the person who lives with him, an unfortunate incident resulted in Harold needing emergency medical care. A home care worker did not show up for their shift, and Johnathon had to bathe Harold, which resulted in a fall. He relates,



Figure 15: Johnathon's bathroom where his care recipient fell, despite having OT recommended a handrail and bath seat

> like that was really, really dangerous. Because I was getting him prepped for a shower. So I was already in the bathroom and just bring his towel over to me and then I will shower him where he has a stool that he has to sit in because he can be on shaky on his feet. So I don't know what happened from the door to the whatever, just like a loud bang and it was a big pile of blood and I was like, oh wow, what happened? ‘I just passed out. I don't know. I passed out.’

Johnathon had basic first aid training from his paid employment (not through the home care agency), but still felt he was unprepared to provide the kind of care needed in this situation. Johnathon believed this situation could have been avoided because he “never got trained how to

properly, like, shower him or move him because the only thing that they have done is an OT came, but not to train me." Instead, the OT assessed the house and simply recommended that a handrail be installed in the bathroom. To feel more confident in his caring, Johnathon had paid out of pocket for educational training on how to de-escalate violent situations but was not offered this through, or reimbursed by, the home care agency. Similarly, Pamela also did not feel like she had received sufficient training for managing her husband's needs and used her own knowledge of pediatric occupational therapy to help her husband with mobility and aspiration concerns. She adds that experimenting with solid foods and liquids was a scary process, as she was never completely sure what might cause her husband to choke.

Amanda received some medical training on wound care, as that is something that home care nursing services do not provide on a long-term basis. After the training from a home care nurse, it became her responsibility to manage her Dad's ongoing skin breakdown issues. Additionally, she was not able to meet with a dietician regarding her Dad's swallowing issues, and it has been largely trial and error to find foods that would not cause him to aspirate. Martha received training from a physiotherapist on how to use a transfer belt, and how to safely get her mom in and out of the house. Although this was useful, Martha felt that too much time was spent on training her, and not enough time was spent working with her mother on rehabilitative exercises.

In passing, Kendra mentioned monitoring her Dad's pills and hemoglobin levels, but felt that most of the hands-on medical care she provides for her Dad takes place in the bathroom. Much to her dismay, she often finds herself cleaning feces. She recounts,

> Kendra: I think I have to talk to home care about that because I'm just having a really hard time when, when he was first really sick he was incontinent and (sighs)...there was...poop. And it was just so hard for me. Uhm, I guess it just, I mean...

Kaitlyn: It's your stepfather

Kendra: Yeah. And it was, I had a horrible time with that. I continue to have a horrible time with the bathroom

Interestingly, when asked, it was not the 'obvious' medical tasks (e.g. medication management and hemoglobin tracking) that Kendra elaborated upon, but her discomfort with bodily fluids. This may be an indication that Kendra has normalized the medical tasks she performs as a caregiver, but cannot reconcile what she feels as crossing a 'social' boundary with her father. Rachel also discussed helping her mother with incontinence. As her mother's condition deteriorated, a decision was made by her mother to use an in-dwelling catheter. Rachel remembers having to empty the bag, and the trolly of medical supplies that "was always in the way," and acknowledged that managing a mother's incontinence is not a common occurrence for a teenager. Thus, this task felt medical to her in the sense that it was outside of her normal role as a daughter.

Tammy manages her mom's medications, and although she does not consider this to be a medical task, her mother wears pull-ups, which regularly need to be changed. (This is something she considers normal, although her mother is embarrassed by it.) Martin also manages his wife's pills, but finds this challenging, as he also takes a variety of medications throughout the day. He emphasizes that "she's always clean. She's always dressed nice. I take her for haircuts…you've got to look after her hygiene and everything. It's a full-time job. It's a lot of work, Kaitlyn." Martin's wife does not have physical limitations that impact her mobility but instead struggles with cognitive impairment. Activities for daily living (ADLs), as Martin described, are often an overlooked aspect of caregiving that can contribute to caregiver burnout. Both Martin and Katherine provided support for their loved ones in the form of ADLs and instrumental activities

of daily living (IADLs), which also include managing finances, grocery shopping, and transportation.

May felt that most of her medical tasks were related to maintaining her mother's cognitive abilities. She encouraged her mom to keep a daily calendar and record things like the weather and what she ate throughout the day. She also encouraged her mother to speak Mandarin and journal regularly. Aside from reminding her mother to properly use her cane, she felt that keeping her mom's mind sharp was the most important medical task she performed.

Georgia had several negative experiences with professional medical staff, both in the hospital and home setting (to be discussed in more depth in section 5.5: Medical Errors), and felt that her husband would be safer if he were entirely in her care. Early in his diagnosis, she did not feel that he was getting enough one-on-one care in the hospital, so she brought him home and "took care of him and nursed him back to health". She made this decision on several occasions as his condition worsened, and later in his decline she continued to take on medical tasks herself. She explains,

> Georgia: Every other day, the nurse would come for his wound. And I learned how to do the wound care.
>
> Kaitlyn: Did they train you on that?
>
> Georgia: I just took it over because I wanted to make sure that it was done right.

The erosion of trust between Georgia and the medical providers meant that Georgia was doing the majority of the personal care and medical tasks for her husband, ignoring her deepening feelings of burnout. Despite having no formal medical training, Georgia believes that if she had disregarded the advice of medical professionals altogether, her husband would still be alive.

Joanne also felt a lack of trust in health professionals and took it upon herself to experiment with her mother's medications. From her perspective, the hospital was "drugging" her mother into compliance and had tied her to a chair to prevent wandering. The pills that the hospital gave her made her sleepy, and Joanne felt that this dose was not medically necessary for her mom. She elaborates on her agentic response, which involved taking on medical management at home:

> … so I came home with the [medication] and they said, oh, it helps with behaviour management. I came home and she was getting, they take a 25-milligram pill, cut it in half and give her 12.5 twice a day. So I did that, for one day. And she walked like this [imitates zombie walking] and she was sleeping. And so, I was like, I can't have her walking drunk and sleepy, that's not her at home. She's gotta move around, we're not doing that. So, I quit it altogether for quite some time. And uhm, I don't know when it was, maybe spring or so, or sometime in summer. She started to get restless sometimes at night and so I felt like maybe she needed some help with sleeping, so I tried 12.5 for a few days and that was, again, it took her too much into the day, so I, for quite some time I gave her 6.25. I cut them into quarters.

Joanne also took over tasks for the home care workers when she observed them not doing the tasks properly. This included stepping in to help with bathing, brushing teeth, toileting, transferring, and respite care with tasks like baking and reading. Joanne regards this as taking over 'medical' tasks, because they should be done by the 'professionals' that were in her home, but instead now had to be completed properly by her.

The narrative often heard by medical professionals regarding recipients of home care is they do not have medical needs severe enough to warrant a stay in a hospital or long-term care centre. However, as detailed by the caregivers I spoke with, there are still a significant number of medical tasks that must be performed, either by a trained worker or an unpaid, untrained family/friend caregiver. The lack of training and 'learn as you go' mentality was stressful for many of the caregivers who did not anticipate these medical responsibilities when considering providing care at home. Additionally, taking over tasks

for that would normally be done by home care workers, or taking on tasks that were outside of their role as a family member, became medical tasks from the perspective of the participants. The home care system formalized their role as caregivers which had the latent impact of turning even 'non-medical' tasks into medicalized tasks. The following section will describe the dangerous side of providing medical care at home, often without proper training, and the darker, sometimes fatal, consequences of placing trust in the medical system.

5.5 Medical Errors: "And then they blamed me"

Iatrogenesis, harm caused by the medical system (Illich, 1976), is an unfortunate reality for those who put their trust in medical practitioners and Western medicine. However, the boundary between medical professionals' responsibilities and family members' responsibilities becomes blurred when services are delivered in the private sphere of the home. The following section outlines instances where medical errors were made (by both paid and unpaid caregivers), the circumstances leading to these errors, and their consequences.

As was discussed in a previous section, the friend Johnathon provided care for, Harold, fell in the shower. Johnathon believed this fall could have been prevented had a trained home care worker shown up for their shift to help Harold in the bathroom. Kendra mentioned that her stepfather had taken the wrong pills in his bubble pack when a home care worker did not come for their shift to give them to him. She feels that she needs to double-check that her father has taken her pills daily, even though this is a task of the home care workers. Amanda addressed that home care workers were limited to the tasks on their sheets and were unable to engage in tasks that would improve her father's quality of life. She notes, "I feel like, in our experience, home

care was the bare minimum to keep my dad alive. It wasn't to help him with a life. Which is so sad. Because a 15-minute walk a day would do wonders for him." Amanda added that because her father had been so independent before his medical event, being moved across the country into his daughter's home to be cared for greatly impacted his mental health. She felt that home care workers were addressing her father's physical needs, but were not able to help him improve mentally.



Figure 16: A cluttered room in Martha's home, due to lack of housekeeping services

Martha broke her foot while rushing through errands to be home in time to relieve a home care worker. She was in a cast for several weeks and could not easily move through her home in a wheelchair. Despite this, homecare did not increase her mother's services and Martha believes that both she and her mother received subpar care during this time. Martha was not given short-term housekeeping and laundry services while she was recovering, which she says allowed the clutter in their home to worsen, making it even harder for her, her mom, and the home care workers to move through the house.

Sadly, both Katherine and Georgia believe that their loved ones died as the result of incompetent medical care. Although not directly the fault of home care, Katherine and Georgia felt that their home care had solidified and formalized their roles as caregivers, and their reliance on these services impacted their willingness to trust medical authorities. Katherine had been

managing her mother's mental health since she was a young child and felt very confident that she knew what was perceived to be 'normal' for her mother. However, once her mother was panelled to a long-term care centre, she noticed a change in her mother's behaviour. In her words she explains,

> Katherine: …she choked to death in the care home. They didn't look at her history when she moved in. And, like she had had a choking episode before. And they also took her off her psych meds a few weeks before she died. Because something is not right, something is not right, and they did it without my consent or without my knowledge. And then, afterward, I asked them, 'she was a little different, was she off her meds'? Something was different. And she went, 'oh, the doctor started weaning her off because we don't believe in medicating the elderly with anti-psychotics'. You know she was schizophrenic! Oh, no, they didn't. Like, this wasn't on intake?
>
> Kaitlyn: Oh, goodness.
>
> Katherine: And then they blamed me because I maybe wasn't there at one of the medication meetings where I was working.

Katherine believed that had she been included in these discussions, or better yet, been enabled through more extensive home care services to continue to provide care at home, that her mother would still be alive.

Georgia also believed that her husband would still be alive if she did not listen to the advice of medical professionals. Georgia had several times before decided to care for her husband at home because she did not feel that he was receiving quality care in the hospital. However, one night when he had been admitted, she received a desperate phone call from a hospital nurse. She recalls,

> Georgia: Except I really fucked up in the last week, I listened to them. You know, I knew that somehow I believed them. That he was dying and, and looking back, I was just, you know, I wasn't eating. I wasn't sleeping. I was traumatized. I was in shock. I've been through all that with [hospital] and taking care of him at home and you know, like. I wasn't thinking. Clearly, yeah. And the doctors made assumptions based on what he looked like.

> Kaitlyn: It's hard when that pressure is coming from you, from that system, and they're supposed to be the authority. But they're also supposed to have our best interests in mind.
>
> Georgia: Yeah, right. And we think they are not supposed to do any harm? Yeah, right! I'll just tell you the final week. He was getting better, I was told by the infectious disease doctor there he could be home in a week. They had him on the proper medication for [condition]. And then I don't know what happened. I got a call in the middle of the night and knowing that I'm there most of the time, right. I got a call in the middle of the night, 3:00 in the morning from the doctor. And she said he's going to either be dead in an hour and a half or a day and can I take him off fluids? What? Yeah. I mean, he was talking, my granddaughters were visiting their grandfather. Yeah. And I agreed I was in shock. I thought there must be a reason she's asking for this. And then a few days later, I said I don't think he's dying. All his vital signs were fine. They said they thought it was like a rebound. OK, so I believed them. And that's where he was dead four days later because he wasn't on fluids.

Georgia mentioned several times that her husband was a victim of 'ageism' by the health care professionals, and instead of treating him like a human being with agency, he was put on a waiting list to die.

Georgia and Katherine expressed a lot of guilt over the loss of their loved ones and ultimately felt that "the system" had made them "complicit" in their deaths, either directly, or due to the role strain of caregiving. Ultimately, Georgia and Katherine's experiences highlight the emotional and ethical burdens that caregivers often face, particularly when they feel powerless within the healthcare system. Their stories, along with those of the other caregivers, illustrate how systemic failures can leave caregivers grappling with guilt and a sense of complicity in their loved ones' suffering. These experiences, however, also shed light on the deep personal connections that drive caregiving decisions. The following section will explore the relationship and identity changes that caregivers in this study experienced, as they took on new 'formalized' roles as 'informal caregivers'.

5.6 Relationship and Identity Changes: "You're a caregiver first, and you're yourself after that"

As I listened to the caregivers' stories, it became clear to me that they had experienced a change in their previous social roles as children, grandchildren, spouses, and friends, to that of a caregiver and/or medical provider. As explained by Heaton (1999), caregiver, as an identity, did not exist until it was identified in policy. This role shift was emphasized as impacting relationships between caregiver and care recipient, and well as complicating the relationship between family/friend caregivers and paid caregivers. Caregivers often did not consider themselves as caregivers until they had some contact with the formal health system. From the perspective of Manitoba's home care system, 'caregiver' is a position that is required, and functions as a manipulable and integral part of the care team (Your Guide to Home Care Services, 2018). This role shift also impacted the caregivers on a personal level as they grappled with whether identifying as a caregiver negated the role they previously held. This section details the complex transitions caregivers endured to maintain and grow their relationships with both the person they were caring for and with medical professionals.

To begin, Martha has almost always lived in a multi-generational home. As a child, she lived with her parents and grandmother, who required home care services. Thus, she states that she has been a caregiver for most of her life, and did not experience a major shift in her identity. She has never lived outside of the home in which she was raised and she always expected to one day care for her aging parents and because of her long-term experience as a caregiver with the home care system, she has grown as an advocate. Similarly, Tammy was able to integrate her role as a daughter seamlessly with that of a caregiver. Regarding taking on personal (sometimes messy) tasks for her mother, she says, "there's nothing I wouldn't do. I don't care about an

[incontinence] accident. It's not a big deal in our world." May also expected to one day be a caregiver for her parents to return the care they had provided for her; a characteristic, she explains, of her Asian culture. Nevertheless, May still struggled to dictate what she felt her mother needed to do to keep safe (not cook, use a walker, etc.) because it is not appropriate in her culture to oppose her parents. To navigate this role reversal, May tries to honour her mother's desire for independence by suggesting 'safe' tasks that her mother could help with, such as making rice in a rice cooker, but not on the stove. In this way, it appears (to her mother) that they are working collaboratively, yet May is able to feel confident that her mother will not hurt herself. She explains,

> I don't know. Maybe sometimes, I think, why am I being overly protective in that way? It's almost like, no, I don't want to keep saying no, you can't. No, don't do that. No, don't do this. It's like. She's my child now, instead of, you know. And I don't have children, so I don't even know. You may be able to tell a child to go to their room and or, you know, sit there and have your quiet time or whatever, but I can't do that with her.

Matters are complicated further when May's mother pushes boundaries without getting caught to maintain independence, such as going down the stairs on her own when May is preoccupied. May explains that she has to "make a deal with" her mom to balance safety with autonomy. In some cases, May has felt that she has had to resort to "threats," telling her mother that if something happens and she falls, they will have to leave the house that they have lived in for 47 years. May knows how incredibly attached her mother is to their home, and this "threat" seems to have the desired effect. It is through this tactic that May acknowledges a role reversal, where she has now become the, albeit sly, authority figure in this relationship.

In contrast with May, Katherine has always felt a role reversal with her mother, as her mother has struggled with her mental health for most of her life. Katherine knew at a young age that she would likely be responsible for caring for her mother as she aged, as she had already

done as a child saying that "because of her mental health history, she was never normal." Katherine also recognized that her mother would not likely be the "sparkly" grandmother who would one day "help out with the [grand]kids," and that she would be a member of the sandwich generation.

Similar to May, Amanda also felt the need to resort to "threats" with her father because his loss of independence was so sudden. She explains,

> I think there's this overwhelming sense that he wasn't quite there yet. I almost felt like they [hospital staff] were trying to like, threaten him (laughs) into sensibility. Because it really felt like it was like a 'smarten up! Snap out of this, or you are going to go into a nursing home' (laughs). So, it almost feels like it was a bit of a wakeup call.

Although he wanted to return home and live independently, the medical professionals did not feel this was an option, thus Amanda had to give her father the ultimatum of living with her and her family or moving into a nursing home. Amanda echoed May's sentiments of balancing independence with safety for her father. For Amanda, her father's decline was incredibly sudden. Her father had gone from independently living across the country, on a remote property that he maintained, to needing assistance with ADLs and IADLs. Amanda felt that both her transition to caregiver, and her father's transition to someone who required assistance, were major adjustments. She explains,

> I think he realized that he needed help, but it took him a while to adjust. So, there were frustrating parts where it was like, 'when are you going to realize this and start acting like you need help'? That total switch of being a caregiver to someone who hadn't really needed care was a big adjustment.

Amanda adds that her father was not used to relying on others for support or managing his time around another person's schedule, having lived independently for so long, while she was not used to being the 'decision-maker' in their relationship. In this way, their relationship changed, mirroring that of a more medicalized definition of 'caregiver' and 'care-receiver'.

Rachel and Maddison both cared for their loved ones when they were children and expressed having to "grow-up faster" than their peers. Maddison felt that this made her more independent and closer to her siblings, while Rachel acknowledged that this negatively impacted her relationship with her mother. She elaborates,

> I feel like there was a point in where I had been really close with her and we shared everything and blah blah blah and then it sort of flipped where she shared everything with me. (laughs) … And then there was a lot of conflict in terms of like being resentful of, she was the parent and needed things, wanted things, to be done at certain times in certain ways, because she couldn't do it herself. And then I was not wanting to do it when she wanted me to do it or [in] the ways that she wanted. And then that was awkward. And that would cause conflicts, I guess. And then, like her relationships with her friends changed. So, then there was a lot of you know, now you're my friend (laughs) kind of thing. Or that she would get upset about things and there was nobody else to talk to, maybe. And then when you're, changing someone's underwear. It's kind of weird. (laughs) It just sort of changes your perspective on the person, I guess. And then they're relying on you for that, then that sort of gives you a little bit of power that maybe you shouldn't have as a teenager or you know, in relation to your parents?

Rachel's experience of conflict with her mother highlights the 'normal' parent/teenager power struggles with the additional challenge of being a caregiver, particularly one that assists with personal care tasks. In some ways, Rachel resented the reversal of roles and having to take on her mother's emotional care needs in addition to her physical needs. However, Rachel also felt that her mother's inability to do certain tasks allowed her some freedom as a teenager that she would not have had otherwise. Rachel also mentioned that her sister and mother had a more complex relationship and that her sister would push back against certain rules. She recalls, "they had more conflict than me and my mom did, and they would start arguing and my mom would say, 'I'm the mom!'" But Rachel's sister felt she could bend the rules and ignore their mother's requests because their mother had "no way to enforce what she was saying."

Martin and Pamela both felt gendered role reversals and have taken on new and additional tasks as caregivers. Pamela admits that her husband "was never that great at helping"

and that she did most of the cooking and cleaning prior to his illness. However, now she must also do 'his' tasks, such as managing the finances, walking the dog, and car maintenance. Martin experienced a more extreme gendered role reversal than Pamela. He explains,

> (wife) used to do all the cooking. I never, I never, I didn't know how to. I never used to cook at home, so I had to learn everything by myself. Even now, I hate cooking, I hate it, I always think, what am I going to make for dinner? What am I going to make for lunch? I just hate the cooking. I never was a cook…. I do the cooking, I do the floor, I do everything. I do everything. I never used to do that before. I used to look after…the grass and do the outside work but I never. (Wife) done everything in the house, she done the canning, the cooking, the baking, she done everything.

This has been incredibly challenging for Martin, yet placing his wife in an institution is not an option for him. Martin often calls on his daughters for assistance with cooking. The gendered role reversals experienced by Martin and Pamela formalized their perceptions of themselves as 'caregivers' in the medicalized sense because they go beyond what they were expected to do before their spouses fell ill. Furthermore, there was an expectation from the home care case coordinators that they *would* take on these tasks *because* they are 'caregivers' and part of the care team.

Kendra reflects, with some resentment, that caregiving has taken over her whole life. She no longer feels like a "happy loving mom" to her children because they are always worried about her well-being. She does not live in a home that is hers, and does not feel able to travel or take on the hobbies she used to enjoy because of her caregiving demands, stating that she is "a caregiver first, and [her]self after that." Kendra took on the role of serial caregiving out of a sense of obligation to her family, but looks forward to when this period of her life will end. She laments, "I don't want to be a caregiver. I would like to be a step-daughter who just comes and says, how are you? Can I shop for you? That's what I would like." Kendra feels immense guilt over these sentiments because she knows her role as a caregiver will end and she will "get her life back"

when her stepfather eventually passes away. Although she does not want this to happen soon, she is also "worr[ies] that by the time [she's] not a caregiver anymore, [she] won't be well enough to do anything," referring to her own health and age. Kendra took several breaks during her interview so she could work through the contradictory emotions she was experiencing.

Pamela expressed similar emotions about the all-encompassing nature of being a caregiver. She explains,

> It's like a job and it supersedes your own needs. You're a caregiver first and then you're yourself after that. Because, I mean, what else are you supposed to do? Unless you can afford to have a live-in support person. Really, everything you do that was planned around them. It's amazing that you know how many appointments and things like that have to be attended to. It is pretty much putting your life on hold I found. I feel, I think [husband] is somewhat aware of that. I don't think he really understands how much work goes into it though. And I think, you know, I do push back on it now and then I'm saying like, I worry that by the time I'm not a caregiver anymore, I won't be well enough to do anything. And certainly, the stress of being a caregiver. It weighs on you. It weighs on your health and stuff like that. On the one hand, you have this great sense of responsibility. To take care of this person. But damn it, I really do want to have a life. I'd like to be doing things you know. Yeah, it's not a positive role, I'd say. He says that he's grateful. Right. Ugh. But there is just no way around it.

Pamela and her husband have discussed the impact of caregiving and the reality of his prognosis, and her husband decided to apply for medically assisted dying. He was approved, and they are working together on a decision for when the right time will be for him to end his life "with dignity."

Georgia also felt that caregiving had taken over her whole life and changed her relationship with her husband. She so closely integrated the spousal and caregiver roles that they became one and the same. She explains, "caregivers are not saints. You do lose your patience sometimes. You know you do it. And it's hard to be compassionate with yourself because you know you love the person. You have a very high standard then of how to care for that person. And any failing is just so difficult to deal with." As previously discussed, Georgia felt that her

inability to stand up to medical professionals ultimately led to her husband's death. She feels this deeply as a failure in her role as a wife and her role as a caregiver. She also adds that it is because of her role as a wife, that she likely did "too much" in her role as a caregiver. Finally, Georgia felt that the introduction of home care respite workers into the home disrupted the closeness between her and her husband. She recounts,

> We tried it [respite] and they were lovely people who came. But there were four different people. And it was like entertaining. We felt, and as I said, we had a very, very tight relationship, married for when he passed last fall for 55 1/2 years, right. So when you're putting someone else into this relationship during the day and they didn't really do much of anything…

Georgia eventually cancelled the respite services because she did not feel they offered the same quality of social connectedness that she was able to provide for her husband, despite this causing her additional caregiving work.

Johnathon experienced the clearest and most abrupt change in becoming a caregiver, as the person he is caring for is not a family member. Johnathon relays that he has always expected to be a care provider and, to some extent, has always worked in paid caregiving roles. When building his home, Johnathon planned for his mother to move in with him and his wife and kept his mother in mind in all aspects of the design process. However, because of his African cultural expectations, his siblings determined it would be best if his mother lived with his sister instead. Feeling this loss and struggling with infertility with his partner, Johnathon says, "I think he came in at a time that I was really feeling empty, and he filled that void." In contrast to the other caregivers in this study, Johnathon was the only one actively seeking the caregiver role. Although their relationship started as an 'obligation' by the agency Johnathon works for, it very quickly became a deep bond that surpassed acquaintance and friend and has now become familial.

It was made evident by all the caregivers in this study that caregiving blurs the distinction between family members and care providers. Caregiving, particularly live-in caregiving, is a role like no other. It comes laden with moral connotations and expectations and supersedes other identities. While some caregivers in this study were able to integrate their role as a family member with that of a caregiver, others grappled with their role and the loss of previous identities. There was often an implicit expectation from home care workers and case coordinators that family members would take on a wide range of tasks simply because they were labeled as 'caregivers' and seen as part of the care team. As a result, relationships that were once grounded in familial intimacy increasingly mirrored a more medicalized dynamic of 'caregiver' and 'care recipient'. In retrospective interviews, such as those provided by Maddison, Katherine, and Georgia, it also became clear that caregiving is not a role that simply 'ends' when a loved one passes away or is paneled to an institution. Caregiving has a way of shaping who you are as a person and leaving traces long after loved ones are gone.

5.7 Decision-making and collaboration: "A bullying kind of system"

According to *Your Guide to Home Care Services in Manitoba* (Government of Manitoba, 2018), "a professional assessment of your individual needs, existing or potential supports, and community resources will determine your eligibility for home care and the type and amount of services you may receive." This implies a top-down approach whereby case coordinators determine what an individual can receive for services, and what should or could be done by your "potential" supports. In the next section of the guide, eligibility requirements, it is made apparent that individuals must "require more assistance than what is available from existing or potential supports," thus home care services are only provided once family/friend caregiver supports are taken into account and/or exhausted. However, later in the guide, it reads that "you, your

family/representative, and your case coordinator will decide on your care plan," implying that family members and individuals receiving care will have some say in how and how much care is delivered.

In many cases, caregivers and care recipients, alike, felt like they had no control over their home care services. Although claiming to be a collaborative process (Government of Manitoba, 2017), many caregivers felt that their knowledge about the care recipient was not valued, that they could not impact the timing or provision of services, or that they did not have any say at all in the decisions made about and for their loved one. In some cases, these decisions were dictated by home care policies. The following section outlines how, and the extent to which, collaboration did appear to occur between and amongst the recipient of care, the caregiver, and the home care providers. Understanding the flow, direction, and intention of power is an essential component of surveillance medicine, thus, it is critical to understand who was making decisions for the home care recipient.

When deciding what was the best living situation for her mother, Katherine was told by a case coordinator that "she's either in a care home or here…assisted living will not take her if she's incontinent." Thus, Katherine felt an obligation to care for her mother in her home. She also recalls that home care policies were "restrictive" because her mother could not get help with housekeeping or meals as there were other family members in the home (thus, implying the family should be doing these tasks). However, after much deliberation, it was agreed that her mother's laundry could be done by a home care worker. Although this seemed at the time to be a welcomed service addition, Katherine felt that it made more work for her and was more disruptive to her schedule, as home care workers were not allowed to touch the laundry of other members of the household. She explains,

> It would be once a week, or maybe twice a week. But again, they would wake me up. I would be sleeping with a newborn and they would be waking me up because they want to use the machine. Oh, 'there is something in there we are not allowed to touch the wet laundry'. You couldn't just put it in a basket? And so, I'd have a newborn. And it would be that constant interruption. You know what it's like, and its like oh, frick, the home care again? And I wanted to be nice to them, and you know, a lot were lovely, but uhm, they were always really loud (laughs) and she couldn't hear. And it's like, I'm just dying.

Katherine goes on to elaborate that the revolving door of home care workers began to feel like an invasion of her privacy and were disrupting the type of home life she wanted her children to have. She elaborates,

> People coming and going from your house all day, throughout the day. Probably at least three times, different workers. And just, tromping around. The social worker, I think she thought I was nasty. It's like, you know, and I said, no. I am just wanting what everybody else wants. I just want a quiet house to raise my kids in. I don't want this mayhem. And I'm told when I can and can't do my laundry. I'm being told when I can and can't go away.

It is evident that Katherine recognized that she was perhaps being perceived negatively by other members of the medical team, but her desire to protect her children and their lifestyle took precedence over the negative perception held by the social worker. Katherine later hypothesized that it was because of the social worker's negative impression of her, that the social worker "pushed" for Katherine to panel her mother into long-term care. However, Katherine was not ready for that step at that time, and was grateful to other members of the care team for supporting her decision.

Amanda also expressed that she felt the home care workers never viewed her as a person with her own needs but simply as a caregiver. She felt that she was expected to collaborate with the system by filling the gaps in home care services and go out of her way to ensure that home care would have to provide as few services as possible, even though she had already bought a new home and relocated her family to take care of her dad. She vehemently describes,

> Amanda: I felt like people totally expected me to stop what I was doing and take care of my Dad and fill in all of the holes in the system. And, that was a really frustrating expectation. And, I'm sure it's frustrating to other people too, but the whole time I was like, I'm his kid! Like, it's not like I'm his partner who's the same age as him that is maybe, like, lived a life and had a career and raised my children already. Like, I'm in the middle of all of that. And you really expect me to do this caregiving on top of school, childcare, (laughs) and work? Or you expect me to like, not do any of those?
>
> Kaitlyn: Right. And you can't just stop being a partner and a mother and everything else.
>
> Amanda: Yeah. I feel like it's just this unreasonable expectation that caregivers will do everything when the system doesn't provide it.

Amanda added that she is grateful for the support of her husband who is able to help her with the caregiving tasks, such as taking her dad to medical appointments. Amanda feels that her husband has more patience for her dad's physical limitations and is able to connect with her dad over their shared hobbies. This relieves some of the pressure Amanda feels for having to "do it all," yet during the interview she grappled with the judgement of others (doctors, home care case coordinators, home care workers) who perceive that she is not a "perfect" caregiver because she can't "do it all."

Kendra felt that she was forced to take on tasks that she did not want to do for her stepfather because she worried they would not be accomplished without her. For example, she explained that her father often 'presents well' and wants to appear independent to the home care workers. She details,

> Kendra: I'm so worried about him, I don't want to go anywhere. Sometimes he won't eat. I've been down there numerous times. Home care will come in, 'what would you like to eat?' And he'll go, 'I'm not hungry right now.' They'll leave, and he'll say, 'maybe I'll have a little something.' So, I...and of course, talking to close people they're like, 'he's using you! Just say no!' Home care does his pills, does his food, does his dishes, and… (sighs)
>
> Kaitlyn: It's hard to say no, though.

> Kendra: How do you say no? 'Maybe I'll have a little something now.' 'No, I guess you starve until they come again...' (laughs). You know, it's tough love. But no (laughs), of course, I'll make him something.

Kendra also mentioned that the annual assessment visits by the case coordinator were not sufficient to evaluate her stepfather's needs. She describes,

> Kendra: I had talked to home care, and they said that (name of CC), who is the coordinator for this area said, well, it's time for an annual visit anyways. So, I'll come over. And I said that I was worried about his forgetfulness and she said, well, I'll come over and we'll kind of do an evaluation... (motions wildly with hands)
>
> Kaitlyn: He passed with flying colours?
>
> Kendra: Yes! It was like, okay, uhm, Dad, do you remember when you put the roast, you put a roast in a pot on the stove and went to bed? And, you woke up with smoke. And he said, ahh, I know, like I never should have gone to bed, I *know* I did that, I *know* I did that. So, (name of CC) is sitting there going like...I'm nuts! (laughs)

Later in the interview, I asked Kendra to recall again the meeting with the case coordinator and to ask if she was able to ask for or was assessed for additional services. She replied, "You know what? Not really. And I thought about that afterwards that. I should have been telling her that I need more help. Like maybe you don't think *he* needs more help. *I do.* But it's sort of all about them, right? And what home care can provide. Uhm, and I guess, knowing that I'm here, I'm sort of the default." The interaction with the case coordinator left Kendra feeling disheartened because they did not believe that her father was increasingly forgetful and required more services. As a result, she questioned her own judgement as to whether her father's needs were actually changing. In this example, standardized testing took precedence over the lived experience of the family caregiver.

Pamela also discussed the insufficiency of the initial home care assessment. Despite having worked in health care, she felt that she "didn't know what was available, so we pretty much just went with the flow." This meant that there were some services they would have liked to have that they did not. For example, I told her about a two-week respite program that is

offered through home care. She wished she had known about this sooner, so she could have taken some vacation time for herself last summer. Additionally, Pamela felt she needed to 'keep quiet' when issues arose to ensure they maintained services. When I asked if they had ever had a negative experience with a home care worker, Pamela related,

> Well, there have been a couple of workers that we declined. There was some that were coming in and they were just really unprofessional. Yeah, you know what? I'm afraid to disagree with them. I feel so dependent on them. That I don't want to get known as being a grouchy client, you know? And without regular contact with your case coordinator, you can't have a conversation, a calm conversation about some of these things. So, I try to keep my mouth shut.

Pamela went on to describe home care as her "lifeline" admitting that her husband would be in an institution without their help. She adds that she has an "interesting relationship with home care" because she is "so dependent on them that [she] lives in fear of losing them," yet she feels the need to "grovel for services" when she needs additional support from the program. This highlights the complex flow of power and authority within the home care system where caregivers like Pamela are positioned not only as family members, but as quasi-patients themselves who are dependent, regulated, and subject to institutional scrutiny. The expectation that she will remain compliant, even when receiving substandard care, emphasizes how medicalized systems can disempower those whom they are trying to support.

To complicate matters further, Pamela believes that home care purposely does not promote all the services they could potentially offer to ensure people do not take advantage of the system. However, this has the consequence of caregivers not knowing that certain services are available, and leaving them uninformed. As knowledge is closely related to power, the breadth and depth of information shared with caregivers is filtered by home care service providers, thus mitigating the power caregivers can have. Martha echoed Pamela's

sentiments saying, home care “don’t tell you these things unless you know how to ask.” Martha believes she only knows the ins and outs of the home care system because she has been a caregiver for most of her life.

Martin also felt disempowered to speak up about service complaints, saying, “I never complain, I just redo things.” He said he did not want to cause any “trouble.” Instead, as discussed previously, he opted to hang signs in his bathroom to communicate tasks with the workers, instead of supervising their daily tasks. As his caregiving role becomes increasingly dictated by the medical domain, there is little room for dissent without fear of reprisal. In Martin’s case, this may also speak to the gendered nature of caregiving. As a traditional man, it was difficult for Martin to ask for help in the first place, viewing this as a personal failure. Thus, ‘complaining’ about the help he didn’t want in the first place seemed to risk making him feel more vulnerable and incapable.

Johnathon felt pressure from the agency he worked for to become a caregiver. Now that he has been providing care, he feels the agency has taken advantage of his caring nature and is blaming their lack of service provisions on COVID-19. However, because Johnathon always seems to ‘make it work’, they are not in a rush to add additional services. Additionally, Johnathon feels the relationship he has built with the person he cares for forces him to continue to provide care because he “doesn’t want to let him down.” Johnathon knows he is burning out, but these pressures are making it difficult to place Harold in an institution.

Joanne felt there was almost no collaboration between her and the home care professionals. Instead, she adamantly reinforced that home care was using a variety of ‘tools’ against her to force her off the public home care system and move to self-and-family-managed care (SFMC). SFMC is a program often suggested by case coordinators for care recipients who

have complex needs or require services that the public program cannot easily provide. It is sometimes seen as a way to 'manage' unpaid caregivers or recipients of care who are strong advocates (i.e. squeaky wheels) (Kuryk, et al., 2023). Joanne does not want to move to SFMC because she thinks her mother is entitled to public care, having paid taxes her whole life, and Joanne does not want to take on the added task of 'management' work. Joanne says the 'tools' began when she started assisting home care workers with her mother's bathroom care. She explains,

> …my mother got aggressive in the washroom and I would help out because I would calm her down. I would ensure that the worker was protected. I would support the worker and it was much easier for me to do that, than to do anything on my own all the time. But I felt like I was made to feel like my mother shouldn't be at home. Like I was getting the impression that she shouldn't be at home. So, in the background there was a sort of feeling and it came in an email where there was, an *incident*. So, they use a few tools. They use a few tools when they start to think like that. I think the removing of the bathing, anything to make it more difficult so that you would say, hey, no, I don't like this so I am going to go to self and family managed care…so, I think the bathing was tool one.

The second tool perceived by Joanne was the feeling that the home care workers were judging the relationship between her and her mother. Joanne recognizes that to an outsider, it could appear that she is yelling at her mother and can be quite short with her. Joanne explains this by saying that her mother is deaf, and she has to speak loudly to her, and that they have always had a relationship where they could speak bluntly with one another. She was told by the case coordinator that home care workers could not stand by while she 'forced' her mother to engage in care, and thus would not provide care for her mother when Joanne was home. She recounts,

> …the workers were instructed that if my mother objected and I, you know, helped her to sit down even though she didn't really want to, that I was FORCING her to go to the washroom and they couldn't take part in that. And they were to leave the room. And leave the situation. And, so, I'm like, okay. So that's the tool, 'we are not going to help you'.

The third tool for Joanne was when she heard from a home care worker that other home care workers were "gossiping" about her and her mother's relationship, and the care that was being provided to her mother. Joanne felt that this was a clear breach of the Personal Health and Information Act (PHIA) and completely broke what little trust she had left in the system. She recalls,

> I have proof that somebody is talking where they shouldn't. So, it took me about a month, three weeks for sure, to pick up the phone because there was a level of anger there that made my stomach crawl. Like, the whole thing, because I know my mother is getting substandard care. I know that they're playing games, using all these tools: not enough care, removing bathing, you know, all of these things. The case coordinator, 'you should go to family-managed care'. 'There's an incident'. So, I know this is all building up. I know that she knows, I told her right off the bat, I am not doing politics with you. And she ignored me. And, I mean, she ignored me, did all their tools anyway, I think they can't help it. I think it's so ingrained in their system that they probably can't help it in a lot of ways. So I complained to the next level up. And I said you know, how do I trust anybody? Like this is my community. I have no way to trust. This is really disturbing. Because we are in a small community, and it's kind of a bullying comment. Like, it's degrading to my mother and it's degrading of a condition that she has no control…And so, you know, it's a bullying kind of comment. Uhm, in a bullying kind of way, using a bullying kind of system. And so, when I called to complain about the PHIA breach, I said, this lady is manipulative and bullying, on top of that. So, the first thing that happened after I called was they ALL WANTED TO RUSH TO THE HOUSE AND HAVE A BIG MEETING IN MY HOUSE. They wanted to REASSESS things. I totally ignored them. I was like, I am not, no! You are not coming into my house… then you want to meet in my home?! After you've violated my trust? I very clearly told you, you have violated my trust! Can you imagine?!

At the time of the interview, it had been six weeks since the initial email had been sent from the case coordinator to Joanne, and she had yet to respond. When word had spread through the home care office that Joanne had filed a formal complaint, she noticed more often than not, respite workers were not coming for their shifts. After asking various home care workers, it was eventually admitted to Joanne that some workers "were not comfortable with [her] in the home, so they're not going to sign up for the shifts, and respite cannot be guaranteed." This infuriated Joanne, and she decided to phone the

director of home care in her region. It was at this time that Joanne was able to review the file that home care keeps on her mother, including her medical conditions and services required by home care. Joanne was horrified to discover her mother was classified as having "severe dementia," a diagnosis that she vehemently disagreed with. The director told Joanne this diagnosis was determined using the standardized Mini Mental State Exam (MMSE)[10] , a test that is commonly used by medical professionals to determine cognitive abilities and deficits. Joanne was frustrated that the MMSE score mattered more than her own experiences with her mother, and questioned if the MMSE accounted for test anxiety or bias due to hearing loss.

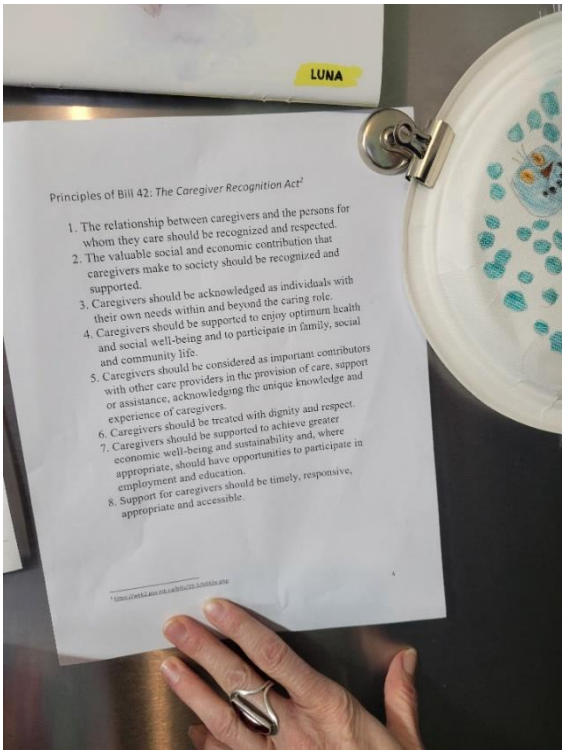

Figure 17:Joanne posting The Caregiver Recognition Act on her refrigerator

In response to the MMSE score disagreement, the home care manager suggested they arrange a meeting with a geriatric psychiatrist and a mental health worker specializing in dementia. Joanne identified this as "the fourth tool," health care workers' ability to "assemble" and "use the power of numbers" to "gang up on" her. She refused to meet with a group of health professionals, and she did not want people she did not trust to continue violating her personal space.

[10] https://cgatoolkit.ca/Uploads/ContentDocuments/MMSE.pdf

Later in the interview, I showed Joanne the list of principles outlined by the *Caregiver Recognition Act.* Joanne had never heard of the Act before and asked if she could keep my copy of the list because she wanted to hang it on her fridge, to compliment the "person-centred care sheet" she had already displayed. She relayed that at some point, she will have to meet with the team of medical professionals, but if they were going to be in her home, she wanted to make it abundantly clear that she, as a caregiver, should be "recognized, respected, and treated with dignity and respect" (Caregiver Recognition Act, 2011).

Like Joanne, Martha is also a strong advocate for her mother and her home. Martha has been a caregiver for several family members and feels that she knows the system quite well. This was verified by a case coordinator who told her that she was,

> …on the ball because [I] knew what was going on. And she says it was difficult dealing with me because I knew what services to ask for, and what home care could provide. But she says 'you're your mom's strongest advocate'. And she says 'I haven't had an advocate like you'.

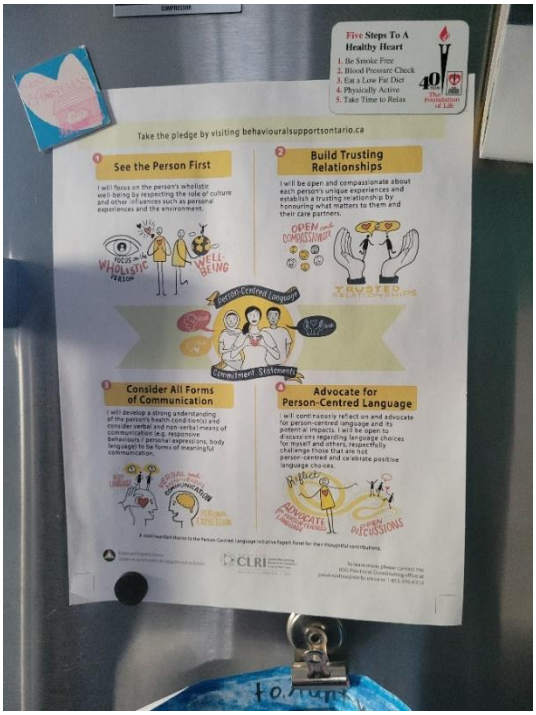

Figure 18: Person-centered care infographic on Joanne's refrigerator

Martha says that she calls the After Hours phone line whenever a supper or bedtime visit is missed and will call the case coordinator regularly if she has any concerns with the home care workers. Martha does not hesitate to provide constructive criticism to the home care workers directly, as she describes in the following account:

> Martha: we had a home care worker show up and she was a fill-in and she came an hour and half late. OK, she could barely speak English. And she came in and said she was there to take my mom to the bathroom. And I said, 'well, you're an hour and a half late. I had to take her so she doesn't have to go now.' Well, didn't the bitch push me aside! She kept insisting she had to take her to the bathroom. So anyhow, she pushed me aside, took my mom. I wasn't going to complain. By then I was just so fucking mad and I had phoned the case coordinator and she said 'I have no idea' and she says, 'they didn't phone you?' I said 'no, I just assumed they weren't coming'.

Martha's biggest concern with home care is the inconsistent scheduling. Oftentimes, workers are sent for a visit when she has cancelled services, usually for a doctor's appointment, or do not come at their scheduled times. Because of her own mental health conditions, she becomes frustrated when her routine is disrupted, explaining, "when home care fucks up, they fuck me up!" Martha explains that because the home care visits are so inconsistent, she has been disregarding her own health. She does not trust that a worker will show up at their designated time, so she has not scheduled herself dentist, hair, or doctor's appointments in several months.

May is also struggling to trust one of her mother's home care workers, but for a different reason. Mobility is a concern, particularly when navigating the narrow staircase in their home. However, one of May's workers has informed May that she is pregnant. May explains her worries,

> May: One of the caregivers right now, she's pregnant. And she's planning to work until the end of January. Should I tell them that I don't want her anymore because she's pregnant? I'm not trying to be discriminating but because walking up and down the stairs and a few times she came here with socks on, on the hardwood floors with socks and you're pregnant. OK, this is the other thing too. So, if let's say Mom has a misstep. She stumbled a little on the steps. Are you going to help her, catch her or whatever? Or are you gonna worry about your own baby? Of course you're gonna like we're humans, right? Because if I have a baby, I'm gonna worry about my baby too. So, are you gonna let her fall?
>
> Kaitlyn: Yeah, I think that's a valid concern.
>
> May: So I'm struggling with that right now because she's a tiny person and she hasn't been really showing like she's not that big right now. And so she just has a baby bump

> now, but it's not like huge or anything, but still it's a baby there. That's the reality of it. So, and I know she wants to work. She needs to work and she wants to work until she's ready to have her baby. So then I'm thinking because sometimes I think maybe I'm being too kind, like and then my sister-in-law said, 'you don't owe her anything. You can if you don't want her, just tell her you can't because of the safety issues'. And then I said, 'well, but she really needs to work right now and she just came to Canada like a few months ago. I think a few months, not even a year'. If I say no and she needs to work, then she'll have less money and she, I don't know, whatever. But that's not my responsibility. So, I'm trying to figure out what is the best way to go with that.

The responsibility felt by May towards her homecare worker's economic situation adds an extra layer of complexity to the collaborative nature of paid and unpaid caregiving. May hires workers through Self-and-Family-Managed-Care, and she is within her rights to dismiss the worker, yet because close relationships often develop beyond that of medical professional and caregiver, she feels it difficult to let this worker go. This, however, puts May in a difficult situation of prioritizing her mother's safety or the worker's financial stability.

Georgia was in a similar situation when she discovered one of her hired self-and-family-managed care workers had lied to her during the job interview. For the protection of her husband's health, it was essential to Georgia that the professionals entering her home were vaccinated against COVID-19. She recalls,

> Georgia: She had told me that she had all her COVID shots and we were masking at the time. Still, because of [husband's] precarious health I asked her about getting a flu shot and telling her we got our flu shots. And she said she wasn't getting a flu shot and I said, 'well, why not?' And she said, 'well, I'm petrified of needles. It was all I could do to get one COVID shot'.
>
> Kaitlyn: So, she wasn't fully honest with you?
>
> Georgia: She lied to me in the interview. She said that she had all the brain that she needed to have. That's how she phrased it…And so, I mean, she was a perfectly nice person, but extremely immature and useless. And she quit. OK, because she thought I was going to force the issue of getting a flu shot. I was just going to ask her to wear a better mask. But she took exception and said she was feeling judged, etcetera. So that was the end of that.

Georgia adds that this particular worker was likely engaging in the recent trend of "quiet quitting," whereby an employee does the bare minimum until they are eventually fired. She was glad that she did not have to fire this worker, and she chose to leave of her own accord. Yet, she still felt "uncomfortable" that she had let someone without vaccinations up to date provide personal care to her husband. Luckily, she adds, her husband did not get sick from this worker.

A final example of lack of trust comes from Tammy. Tammy has a tumultuous relationship with her sisters and extended family members and believes that they steal from her. To prevent this, Tammy has installed a surveillance camera in her living room, which is against home care policy. She explains,

> I did have a camera in the living room. Which you're not supposed to have, right? So I can just check on things. And one lady noticed it, and she left. Which was fine. The coordinator called me, and I said yes. I have a camera in the living room. I said simply. Because at that time, we had lots of family you don't want around. And things were missing. So I put the camera directly at the door so I could watch them. I said that's the only reason it's there. Anyways, the camera is still there. Nobody's complained about it. I don't even look at the camera. These two ladies I know, I don't have to worry about them.

In this account, Tammy had built enough trust with the regular home care workers that they were not concerned about the camera and understood Tammy's desire to keep an eye on her family members. However, this is still something that Tammy needs to mention to one-time-only workers because surveillance is not permitted in home care policies.

Despite the stated objectives of the home care program to be collaborative in its approach by including family members and recipients of care in the planning process, it was felt by most caregivers in this study that they were not equal members of the care team. In many cases, caregivers felt that their expertise was ignored and if they did not comply with suggestions made

by home care and medical professionals, they would put their loved ones at risk of being denied quality care. Thus, it became an ongoing struggle to balance advocacy with compliance. To complicate matters further, the family/friend caregivers also navigated the needs and wants of the people they were providing care for while trying to navigate their roles as care providers. In many ways, this complex web of interactions left family/friend caregivers feeling overwhelmed and undervalued.

The findings explored in this chapter illustrate how the boundaries between home and institution, caregiver and medical professional, family and system, are often blurred with the introduction of home care. As caregivers take on increasingly complex medical responsibilities, navigate difficult dynamics with health professionals, and adjust to the physical and emotional transformation of their homes, it becomes clear that these are not isolated experiences, but part of a broader structure of power. What emerges is a system where the ideals of "home" and "care" are reshaped by institutional procedures, norms, and expectations. In Chapter 6, I incorporate a Foucauldian framework to make further analytic sense of these shifts, drawing connections between caregivers' everyday experiences and the broader processes of medicalization and surveillance medicine. This discussion also considers what these insights mean for future policy and practice, and where further research might support more responsive, caregiver-informed approaches to home care services.

Chapter 6: Discussion and Conclusions

6.1 A Foucauldian Understanding of Medicalization of Homecare

The narratives of the caregivers in this study are inspiring, yet sad, unique, yet familiar, and brutally honest. The experience of providing care to a loved one is something that everyone will likely undertake in their lifetime, but is often not considered until it is necessary. Care is often offered in a crisis state forcing caregivers to rely on the expertise of medical professionals, and/or provided for long periods of time where care tasks that were once novel become normalized and integrated into daily life. This chapter uses Foucauldian conceptualizations of medicalization to sociologically understand the experiences of the caregivers. Taking a cue from Frank's (2002:16) "counterintuitive presupposition" concerning medical consumerism, "that the effects…may ultimately be as great and possibly greater, on those who do not receive these services, but who live in a society of which these services are a part" thus homecare does not just affect the individual who is receiving the care but also has an impact on the family who lives with the individual, and indeed, with our wider society. Following Frank, it is important to understand how the 'common-sense' perception of bodies and lives are affected by the current home care regime and supporting discourses. In a Foucauldian sense, family caregivers participate in the gaze of medicine when they engage in the home care network. As caregivers come to define themselves as such, surveil the home care recipient, and monitor their own values and behaviours to model appropriate behaviours as defined by home care services, they themselves become medicalized.

When patients are in a hospital, the patient is at the centre of care, with the focus of medical intervention being the signs and symptoms within the patients' body (Armstrong, 1995).

However, home care allows the institution of medicine to enter the home. A shift in the temporal space of care into the home results in a shift by which the families of the care recipient are viewed by workers as an extension of the care recipient (Benzein, Johansson, & Saveman, 2004). The caregivers in this study note a variety of ways in which they felt they were 'made visible' to medical providers, including judging relationships they had with others, how they chose to spend their free time, and the state in which they kept their homes.

To complicate matters further, home is generally a place where rules and social norms are relaxed (Buse & Twigg, 2014), but this boundary may be blurred when guests are home care workers entering the home (Jacobson, 2009). For example, Joanne felt that the home care workers were scrutinizing the relationship between her and her mother. Because Joanne and her mother regularly communicated in ways that were boisterous and blunt, the home care workers felt there might be abuse in the home and did not want to condone that behaviour. Joanne believed that the communication strategies between her and her mother were justified (her mother is deaf) and that she was being penalized for trying to help. Ultimately, the surveillance and judgement from the home care workers led to a reduction in services for Joanne's mother; something Joanne describes as 'punishment'. Joanne thus became the subject of disciplinary power (Foucault, 1977).

From the perspective of the home care workers, the homes in which they are providing care are workplaces. Family/friend caregivers in this study expressed that, in some instances, workers did not consider that they were working in someone's home and instead treated their home like an institution. In cases where family caregivers asked the workers not to come back, it was because they felt the worker was rude and disrespectful of the home space. In a hospital, for example, medical providers know that there is a separate cleaning staff that will ensure the

cleanliness of the space. However, in a home, this is the dual responsibility of the worker and the people in the home. In most cases, tidying tasks are not on a worker's task sheet, thus, they do not have a formalized responsibility to respect the home in this way. For example, in a hospital, all towels may be used by everyone and are washed after each use. However, in a home, some towels may be categorized as 'communal', 'fancy', 'guest' etc. These distinctions can be essential to maintaining one's sense of home and is not always top of mind for workers, as evidenced by Martha and Joanne.

In keeping with regimenting homes to mirror institutions, home care workers are provided a task sheet, which outlines what needs to be accomplished with each recipient of care. These task sheets standardize care and help to ensure that workers adhere to their schedules but from a Foucauldian perspective (1977), regiment time to create docile bodies and enforce power. As such, it is not just the tasks themselves that indicate a display of power, but when the task is conducted that serves as a form of control (Foucault, 1977). While this may promote efficiency, it also promotes obedience and makes surveillance easier (Foucault, 1977). From the perspective of the family/friend caregivers, the task sheet did not address the ever-changing needs of their loved ones and did not account for the unpredictable nature of the home environment. Additionally, the standardized nature of the task sheet reduced the care recipient to their perceived deficits and did not foster holistic insight into the person they were providing care for. As highlighted by Joanne, family/friend caregivers are not able to view the task sheet provided to workers and thus are not able to add additional contextual information. By organizing home care services into tasks and checklists, the institution of home care is able to keep a record of the recipients' health (and obedience) history. This serves a dual purpose: (1) separating the body from the person, and (2) gaining knowledge about the recipient of care. Thus, task sheets serve

as an institutionalized mechanism of surveillance medicine (Armstrong, 1995). Furthermore, as the time allotted for each care task continues to decrease, there is less time available to dedicate to more holistic care approaches, such as socializing.

Once included in the scope of care, accepting home care influenced the subjectivity and social roles of the live-in caregivers. The families' dependence on the services and the need to conform to the scheduling and organizational priorities of the system in many ways was interpreted as minimizing their relative power within the home. This transition was a struggle for many of the caregivers in this study, as they also navigated their caregiving roles and newfound authority as formalized members of the care team (regardless of the amount of influence they felt they had on care decisions).

Although caregivers felt their agency within the home had been reduced in deference to home care providers, their power and authority over their loved ones generally increased, illustrating the complex web of biopower (Foucault, 1978). Rachel felt that providing intimate personal care for her mother ultimately resulted in a role reversal where she became the provider for her mother, while Maddison suggested she took on a 'parental' role for her siblings, while her mother (Katherine) was providing care to her grandmother. May noted the friction she felt between managing risk for her mother with her cultural understanding of respecting the authority of elders. Therefore, the change in the subjectification of live-in caregivers within the hierarchy of the home, due to the presence of home care services, can be described as a medicalizing feature of home care. Aligning with Rose's (1998) argument, it is this "ambiguous set of relations" between actors and diverse authorities that serves as a tactic through which power can permeate.

In addition to changing social roles, some live-in caregivers' narratives reflect having been medicalized by the language they used when describing the tasks they undertook. For example, Georgia stated she "nursed" her husband back to health, literally implying that she was the medical authority in this situation. Her use of the word 'nursed' reflects the internalization of medical tasks that fundamentally changed her role from wife to 'nurse'. Thus, she is an active participant in the medicalization of her subjectivity. Additionally, Kendra told me that she did not perform medical tasks for her stepfather, yet later mentioned monitoring his hemoglobin levels. This dismissal of tracking oxygen levels in the blood speaks to the integration of medical tasks into Kendra's role as a stepdaughter. Undertaking this medical task no longer appears medical to her, but simply part of what she does as a caregiver. The internalization of 'obvious' medical tasks, into less obvious 'informal' or 'social' care tasks, indicates the completion of the medicalizing process. Like Georgia, Kendra, too, has been an active participant in the medicalization of her identity, as she normalizes the new medical tasks she performs. Thus, caregivers had fully engaged in a regime of practice (Dean, 1999) whereby power operates through self-governance, and not through overt control.

Moving beyond the individual, every caregiver in this study had to make some form of medical adaptation to their home in order to provide care for their loved one. These adaptations were always suggested by a 'team of medical professionals' after their homes had been assessed for various types of 'risks'. From a Foucauldian perspective, homes themselves can be perceived as deviating from normal, wherein the 'normal' state is that of the medical institution. Thus, adapting 'the madhouse', a deviant and risk-laden space, in a variety of ways can be perceived as an attempt to bring back 'normality' as defined by medicalized institutions (Dyck, et al., 2005). During the home assessment, occupational therapists would come into the caregiver's home and

identify instances of risk and opportunities for risk-reducing technologies. Labelling the home as a site of potential risk negatively impacted the live-in caregivers' perceptions of home, which often was described as a place of 'safety'. Despite this, these 'risk-reducing' suggestions by medical authorities were more often than not taken, and medical technologies were installed, thus highlighting the power of medicalized discourse.

Jacobson (2009) argues that we have been learning how to dwell since childhood, and that home is not a separate part of experiences, but is intrinsically ingrained within us and even has an influence on personality development. Home is like a second body and can provide us with safety and comfort (Jacobson, 2009). Thus, rearranging objects in a person's home, as often happens with home care services, can impact a person's feelings of security and safety, and impact habitualized behaviours. This is most clearly demonstrated by Martin and his discomfort with having the living room table off-centre to the window. While this may not be a big deal to some, and would not be others be considered a "medical technology", the table represents the decline of his wife's health and serves as a daily reminder that their lives have irrevocably changed. Thus, the consequence of moving the table is a medicalized adaptation.

More obtrusively, entire rooms in Georgia and Pamela's homes were converted to better meet the medical needs of the person for whom they were providing care. These changes were often made at the discretion of the caregiver, but had the impact of separating the new medicalized room from the normality of the rest of the home. Walking into Pamela's home, being in her kitchen and living room, there was no indication that someone living in the home required medical care. Even during the interview, Pamela did not acknowledge that her and her husband slept in separate beds because his medical condition was disrupting her sleep. Thus, keeping the medical technologies sequestered in a single room is one way that Pamela prevents

the medical technologies from infiltrating other aspects of her home. In this way, Pamela is able to limit the physical reminders of her role as a caregiver, effectively resisting the reach of the medical gaze. While 'strategies of containment' are often used by individuals in their homes to protect their private space from others (Santos et al., 2024), added complexity is introduced when this containment is from members of the 'public' and not residents of the home.

In contrast, Georgia was not able to compartmentalize the medical technologies in her home. Georgia converted the library in her home to a hospital room for her husband. When I asked her, after her husband passed away, if cleaning out the room helped with the grieving process she responded by saying, the caregiving "never ends" as there are always "constant reminders." Here, Pamela highlights the pervasiveness of the medical gaze and the internalization of the caregiver identity. The power of the gaze is so pervasive that she continues to feel it even years after her husband passed away and has not been able to convert the hospital room back to a library. Effects of the medical gaze were felt long after their caregiving roles ended for Katherine and Maddison, who both distinctly remembered the smell of urine when thinking of 'home'.

Because Johnathon was providing care to his friend through a private agency, he had extra procedures that needed to be followed. Johnathon detested the fire extinguisher on each floor and displayed escape room plans, saying they made his home feel like an "institution." These markers of 'safety' made him feel that his house was only a site of risk, and did not contribute to the sense of comfort that he wanted in his home. What frustrated Johnathon more, however, was the agency's requirement of screening and moderating other people who come into his home. If someone were to stay more than 12 hours in Johnathon's home, they needed to provide a criminal record check and additional background information to the agency before

their stay could be approved. Johnathon felt this contradicted the 'open door' policy he grew up with and disconnected him from his friends and family. From a Foucauldian perspective, the expectation that guests in Johnathon's home make themselves 'visible' and 'known' extends the radius of the medical gaze. In this way, the agency, representing medical authority, learns more about people in the general population and is able to manage the people that Johnathon lets into his home.

Notably, my research suggests that home care not only alters the home space but can medicalize and change the relationship of family caregivers as they become both subjects and agents of their own medical surveillance. Family/friend caregivers are in a unique position as they surveil the work of medical professionals while simultaneously being surveilled by the medical professionals. In this way, the flows of medical power and authority become more complex and nuanced. Joanne and Martin both described the need to 'watch' the home care workers provide care to ensure the tasks were being completed appropriately but recognized the intrusion of their surveillance on the workers. In many instances, home care workers are themselves marginalized. As such, they themselves are beholden to a regime of practices (Dean, 1999), which grants them little power over their care decisions in deference to the bureaucratic health care system. This is often recognized by the informal caregivers who do not want to place additional hardships on the paid workers. For example, May felt conflicted as she wanted to keep her mother safe, but also felt an obligation to protect the home care worker and her unborn child. She did not want to fire the pregnant worker as this would negatively impact her financial situation, yet she wanted to ensure her mother continued to receive quality care. Worrying about the well-being of the workers may not be an issue for caregivers when care is being provided in

an institution, but because it is provided in the home, the relationship between the paid and unpaid caregivers becomes more complex.

A Foucauldian analysis suggests that the increasing invisibility of governmentality in modern society (Foucault, 1977) means that surveillance is invisible and constant, but that the mechanisms of this surveillance are not readily visible to those surveilling because that is 'just what they are supposed to do' (Hill, 2009). Therefore, family members may feel as if they are making a choice on their own; however, it has been influenced by current neoliberal discourses. This is most clearly evident when caregivers, such as May, Katherine, Georgia, and Rachel, describe the functional nature of 'family' to help out and provide support. In a neoliberal society, public discourse suggests that family members should be the first resource for a person in need of care and public services should only be used as a last resort (Dalmer, 2019). Thus, providing care as a family member becomes laden with moral responsibility that ultimately supports neoliberal governance of health. Here, responsibilization is at work, where individuals are subtly expected to take on the burden of care as a personal obligation rather than a collective social concern (Palęcka, 2024). Paired with prudentialism, where caregivers are encouraged to make 'wise' and 'responsible' decisions, like minimizing public service use, caregivers display internalized norms of good citizenship and moral duty without the need for direct coercion (Palęcka, 2024). This is emphasized by Georgia admitting she likely provided more care than she should have to her husband at home because it was her 'responsibility' as a wife to do so.

In some ways, pushing the family/friend caregiver to take on more (and more medical) tasks than they were willing or comfortable to originally undertake allows the medical gaze to extend further into the lives of the informal caregivers. Part of the reason Kendra does not want to move out of her late mother's apartment is that she worries that if home care workers do not

do their assigned tasks, then the care for her father will not be provided at all. While she considered a tough love approach, she ultimately feels it is her responsibility to ensure quality care is provided for her father. Her willingness to provide care has impacted all other aspects of her life, including her relationship with her children, her sense of self and self-esteem, and her general outlook on life as she ages. Kendra feels completely dependent on the home care system, while the system continues to function entirely dependent on her.

The ultimate goal of surveillance medicine is to exert biopolitical control over populations by reinforcing medical authority (Armstrong, 1995). Thus, it is not surprising that once home care had integrated itself into the home, caregivers became dependent on it. Pamela acknowledged this dependency directly by saying home care is her "lifeline" and her husband would not be able to live at home without them. Many caregivers held this sentiment in this study, as their filial obligations to their loved ones meant they would 'put up' with the negative aspects of home care, such as lack of communication and inconsistent scheduling because the alternative was putting their loved one in an institution. Thus, adhering to the rules of home care felt like their only option, reinforcing their reliance on the medical system. As Foucault (1975) wrote, "I am going to see to it that you are free to be free" (p. 63), thus many caregivers felt they were beholden to home care, and only able to live their lives within the boundaries of what home care was able and willing to provide. Their limited 'freedom', as determined by case coordinators, timesheets, and standardized assessments, impacted their quality of life in numerous ways, including basic necessities like booking doctor and dentist appointments to work and social obligations to maintaining relationships with other friends and family members.

The intake assessment was the first time many caregivers realized that their knowledge of the care recipient was being superseded by medical authority. Although caregivers were asked to

be at the intake assessment, they did not feel like equal partners in the care plan. Several caregivers acknowledged that they simply went with the flow, as they assumed the home care program knew what was best for their loved ones within the realm of what the services were able to provide. However, it was also at this time that the caregivers noticed their role had shifted. None of the caregivers were asked about their own needs and what home care could do for them to ease caregiver burden. Instead, caregivers were positioned and formalized as 'resources' that were assessed in terms of what they could provide for the care recipient. Thus, caregivers were not viewed as individuals in their own right, with families, work, schooling, and other obligations. However, it was expected of the caregivers to adapt these aspects of their lives to continue in their role as caregivers.

Throughout their times as caregivers, many continued to feel that their knowledge of the care recipient was ignored in favour of standardized medical assessments. Joanne disagreed with her mother's designation of severe cognitive impairment as determined by the Mini Mental State Exam. Katherine felt the long-term care centre's blanket policy on anti-psychotics negatively impacted her mother's health. Georgia was told by hospital nurses that her husband's vital signs and test results indicated death was imminent. Relying on the medical model's perceived superiority instead of the caregiver's experiential knowledge resulted in negative outcomes for all three of these caregivers' loved ones. Joanne's mother received poor quality care that only attended to her basic needs, and did not receive care that would improve her quality of life or cognitive abilities because the label of 'severe cognitive impairment' in her file meant no improvement could be made. Katherine and Georgia both felt their loved ones died prematurely because they had listened to (or had been forced to adhere to) medical advice.

Ultimately, the recognition of the dominance of medical authority left caregivers feeling "disempowered." In the literal sense, their power in their homes, in their roles as family/friends, and their role as caregivers, had been stripped from them. According to Foucault in *Discipline and Punish* (1977), when a subject becomes disempowered, they are easier to manage, thus, creating space for other forms of power to dominate and become internalized. In some cases, when caregivers stood up against medical authorities they were met with resistance. Sometimes, this resistance was subtle in the form of delayed communication and the passing of responsibility from one person to another. In other cases, this resistance was more forward, with the threat of cancelling services altogether, or personal attacks against the caregivers for demanding too much. Therefore, to avoid conflict and the hassle of dealing with the bureaucratic system, caregivers more often than not opted to submit to home care workers and policies with little resistance.

Foucault (1975) also argues that subjects that are willing to self-surveil and bring themselves back in line with social norms are viewed as 'good subjects', just as it is suggested that compliant home care recipients and family caregivers are viewed as 'good patients' by medical professionals when their directives are followed. Being a 'good care provider' was internalized by the caregivers in this study, as they recognized that going against the advice recommended by medical professionals could result in substandard care for their loved one. Further, these sentiments reflected the female caregivers' desires to be viewed as 'good daughters', or 'good women' more generally. Katherine had the impression that the care coordinator felt she was "nasty," and this ultimately led to her mother being paneled to a long-term care centre. Martin states that he does not want to cause "trouble" and opts for more subtle forms of ensuring his wife receives quality care. It is also important to note that when informal

caregivers were asking for more services, they felt as if they were 'begging' and needed to ask permission to make their lives more manageable. In this way, caregivers were encouraged not to ask for additional supports, while simultaneously being reliant upon that support. When someone feels like they need to beg for support, they recognize they are the individual in the situation with less power and are thus beholden to the more powerful medical authorities.

Paradoxically, caregivers who embraced neoliberal conceptions of self-responsibility were subtly moved out of the system. However, this is not surprising as Rose (1998) surmised in his conceptualization of Foucault's work that "the autonomous subjectivity of the modern self is itself a central feature of contemporary governmentality" (p.152). Caregivers, such as Joanne and Martha, who were considered by the home care system to be 'advocates' for the person they were providing care for, or in other words, those who could not as easily be 'managed' by the system, were pressured to leave the home care program altogether. This meant that the person in need of home care services would not receive any services at all, or had the option of moving to self-and-family-managed care. From the perspective of the live-in caregivers, Self-and-Family-Managed Care is not an appropriate solution as it would mean the caregiver would have to do even more work than they were already doing (making schedules, recruiting and hiring workers, managing payroll), thus having the consequence of worsening the burnout that the caregivers were already experiencing. In that way, the home care program was able to keep even the loudest advocates quiet and controllable through the use of threatening alternatives. It should be added that, even when caregivers in this study were providing care through Self-and-Family-Managed Care (May and Georgia), they were not able to avoid the reach of the medical gaze. Neither felt like they had more autonomy in determining care decisions and both ultimately continued to defer to the authority of medical professionals.

In keeping with Foucault's (1978) conception of biopower, Joanne felt there was a series of 'tools' used by home care to keep her in line. These 'tools' were multifaceted and enacted by multiple members of the care team. The 'tools' included suggesting she leave the program altogether because she was expecting too much, judging the relationship between her and her mother, workers gossiping about her and her mother, and using the 'power of numbers' to 'gang up on her'. Joanne herself interpreted these tools as forms of medicalization, because they were being used against her by medical providers. For Foucault (1977), these 'tools' would be considered 'technological' in that they seek the calculated orchestration of the activities of humans under practical rationality directed towards certain goals. They attempt to simultaneously maximize certain capacities of individuals and constrain others in accordance with particular knowledges (medical, psychological, pedagogic) and toward particular ends (responsibility, discipline, diligence, etc.)"(Rose, 1998, p.152-153). These 'tools' and 'technologies' left Joanne feeling unsure of who she could trust not only in her home but in the larger community in which she lived. Further, this surveillance went beyond the care that Joanne provides to her mother, to surveilling their relationship, their home, and the relationship Joanne had with others in the community. Joanne felt the only power she had against the home care 'bullies' was to refuse them entrance into her home.

Joanne commented on the 'numbers game' that home care was playing with her. She felt that not only was home care trying to undermine her own authority in her home, but this was being accomplished through a series of medical professionals. Other caregivers in this study commented on the large number of professionals they were dealing with, including doctors, home care workers, home care case coordinators, schedulers, occupational therapists, physiotherapists, and social workers. As 'experts of subjectivity' (Rose, 1998), these

professionals used their credentials and authority to undermine the knowledge of a single caregiver and ensure the caregiver adhered to professional standards and suggestions, which oftentimes meant changing the home in ways that resembled standardized institutions. As such, medical discourse continues to establish itself as the authority by which individuals come to understand themselves (Rose, 1998).

Not only do numbers serve the purpose of showing strength, but from a Foucauldian orientation, the more knowledge one can gain, the more power one holds (Foucault, 1975). As knowledge is gathered from multiple medical professionals to learn about various aspects of the care recipient and their family caregivers' lives and health histories, the more power that is granted to the medical institution, and by extension, the more powerful the team of medical professionals becomes relative to the knowledge held by the care recipient and family caregiver. Thus, with each new member of the care team comes an opportunity for the gaze to extend its boundaries. This accumulation of specialized knowledge not only reinforces structures within the medical institution but also enables more detailed and continuous surveillance of the care recipient and their caregivers, effectively transforming them into an object of analysis and intervention under the medical gaze.

Because the goal of medicine has shifted from healing to surveillance and authority (Armstrong, 1995), home care services in their current form are not designed to be rehabilitative or health promoting. Instead, family caregivers in this study, like Joanne and Amanda, believed that home care is only doing the bare minimum to keep their loved ones alive, while others like Martha and Georgia acknowledged that home care services are only offered on an as-needed basis, not for prevention. Pamela insightfully noted the distinction between home care case coordinators asking, "what do you need" instead of saying, "this is what we can provide for

you." This subtle, but important difference refocuses the onus of responsibility to the family/friend caregiver to provide the bulk of care instead of the home care workers. From a Foucauldian perspective, this distinction also reveals how power operates through the production and regulation of knowledge. Medical authorities, such as home care, do not just possess information, they control its flow, determining not only what knowledge is made available to caregivers, but also when and under what conditions it is disclosed. As a result, institutional authority is reinforced by managing access to information. Four caregivers in this study did not know about programs offered by home care services until I informed them during the interview.

When discussing the onus of responsibility when something went wrong, such as injuries or deaths, the live-in caregivers believed that they were the ones who were held accountable. Although forced to rely upon medical advice and technologies, the caregivers felt 'complicit' in negative outcomes experienced by their loved ones. As theorized by Ivan Illich (1976), the expansion of medical authority would also lead to an increase in iatrogenesis. However, because the homes and the live-in caregivers were medicalized by home care services, they were ultimately the ones viewed as responsible for the medical errors, not trained medical professionals. Further, caregivers were made to feel by the home care providers that they failed in both their role as pseudo-medical providers and in their role as family members or friends. In this way, the very system that medicalized their homes and enlisted them as extensions of professional care also positioned them as scapegoats for its failures, burdening them both with the weight of medical responsibility and the lasting sting of personal guilt.

In summary, caregivers experienced the medicalization of themselves and their homes in many ways. They felt rendered visible to the home care system in ways that scrutinized relationship dynamics, assessed the state of the home, and evaluated their use of leisure time.

Engulfed in the web of biopower, they often felt a muted sense of agency whereby they navigated the complex social relations of surveilling their loved ones and surveilling the workers, while simultaneously being surveilled themselves. Caregivers were aware of disciplinary techniques and consequences that often influenced their decisions to adhere to the medical model, and engaged in various risk reduction techniques through the introduction of medical technologies. Finally, caregivers ultimately internalized and normalized their new roles, embracing medicalized language, procedures, and environments. Moving forward, there is more that needs to be done by both policymakers and researchers regarding informal, live-in caregivers of home care recipients, and it is to this that I turn in the next section.

6.2 Policy Suggestions

This research suggests applied changes that can be made to the home care program for the benefit of informal caregivers. To begin, during the initial home care assessment, caregivers should be asked first if they want to continue in their role as caregivers, and to what extent, not simply expected to continue as a resource or 'back-up plan'. Despite not being a 'guaranteed' service (Government of Manitoba, 2017), home care would have to respect the decision of informal caregivers if they choose to set boundaries for their caregiving responsibilities and ensure the person receiving care does not suffer the consequences, such as a reduction in the timing or frequency of care. This could help to minimize the power differential between formal and informal caregivers. Going one step further, the Manitoba Home Care Program could work to become a guaranteed service, which would eliminate the need for a family/friend back-up plan altogether. Family/friend caregivers would then have the ability to provide care how they want, and when they want, without the imposition of home care guidelines, policies, or schedules.

Next, if caregivers choose to be included in care and care decisions, they should be assessed not as resources, but as people. This would mean holistically understanding their needs in ways that would go beyond the standardized nature of the intake forms in a way that centralizes the caregiver. This would help to reintegrate the 'person' back into the 'task-based' focus of home care services and minimize time and structure as a tool of disciplinary power. Moreover, the principles of *The Caregiver Recognition Act* should be put into action. It was mentioned by all caregivers in this study that the *Act* sounds good in theory, but more needs to be done to ensure they are valued, recognized, and respected in their role as caregivers. This could include creating a formalized Caregiver Advocate role to assist in policy and procedure changes. If the principles of this Act were enacted, it would be important to ensure that caregivers, regardless of their integration with formal services, be recognized. For example, if a friend or family member chooses not to be involved as a formalized 'back-up' plan, their contribution to care work should not be minimized or discredited. It should not only be through the recognition of caregivers, as established by medical discourse and standardized assessments, that family and friend care providers be entitled to support and recognition.

Following this, caregivers and home care providers alike should be educated on how homecare services may alter their environments and relationships. Oftentimes, families choose home care services because they do not want their loved ones in an institution, without the awareness that their home might become institutionalized through medical technologies through home care. These technologies may require additional knowledge and training that not all caregivers want or have the capacity to manage. Furthermore, these medical adaptations can be expensive and, in some cases, can permanently alter the home. Families should be made aware of

the financial measures they may have to undertake, especially those with fewer monetary resources.

Finally, home care providers should be trained in ways that incorporate the unique challenges of providing care in someone's home in contrast to the standardized environment of an institution. This could include a whole range of new environments and techniques, including practicing lift assists and transfers in cluttered spaces, navigating home with multiple levels or steep staircases, and managing care in settings with loud noises and other household distractions. Training should also address how to use improvised 'equipment' or adapt to a lack of hospital-grade tools. In cases where family/friend care providers or the recipients of care decline medical adaptations, they may have alternative supports that they use to ensure functionality and reduce risk. At the scheduling level, it would be important for new workers, recipients of care, and family/friend care providers, if they choose, to have scheduled time to build rapport with one another and learn how to use some of these alternative tools. Time should also be given for the workers, care recipients, and family/friend care providers to learn about one another beyond tasks on a standardized list. Learning about the likes, dislikes, preferences, and idiosyncrasies of people will help to ensure that the home environment continues to feel homey and less like the impersonal nature of standardized care settings.

It is important to centralize the care recipients' conceptions of 'home' into the care plan, to ensure it remains a space of comfort, autonomy, and personal meaning, rather than one of surveillance and control. By acknowledging the emotional, cultural, and symbolic significance of home, care can be delivered in a way that respects the boundaries and identities of those receiving it, and the boundaries of other members of the home, to ultimately foster a more collaborative caregiving relationship.

6.3 Limitations and Future Research

This research is the first of its kind in Manitoba to describe the ways in which home care services function as agents of medicalization. Home care services extend the medical gaze into the private sphere of one's home by standardizing the home into a site of risk that needs to be managed, and medicalizing live-in family/friend caregivers as they internalize the language, roles, and tasks of the medical model. Informal caregivers serve as subjects in their own medicalization while simultaneously subjecting the people they are providing care for. Finally, the dependency with which caregivers become reliant upon formalized care systems can ultimately make them complicit in medical errors. Further research should investigate how to control the pervasiveness of the medical gaze, in ways that allow caregivers and care recipients autonomy over care decisions. This does not necessarily mean to eliminate the medical gaze altogether, which could result in restricting the use of medical technologies, but would grant caregivers and care recipients more control over the process. This would, by extension, minimize the harms caused by imposed reliance on medical systems. Additionally, a longitudinal study would capture how caregivers' role and perceptions shift with prolonged exposure to the home care system. This would also address how roles shifted as the care recipient's prognosis progressed and could thus capture the changing medical needs over time.

Qualitative in design, this research is deeply context-specific and should not be generalized to the experiences of all co-residing caregivers. As a complete member researcher with the potential for bias, this research could be replicated by researchers who are not caregivers, or have not lived with a recipient of home care. This may provide a more objective understanding of the experience of medicalization by home care services. Additionally, an

external review of the codes and coding process would have helped to ensure inter-rater reliability.

Limited in ethnic diversity, further research could also investigate how cultural expectations impact filial responsibility and integration with home care services. While cultural differences were alluded to in this study, only two participants did not identify as white. Further, this study focused primarily on the Winnipeg Regional Health Authority, with only one rural health authority participant. Future research should focus on additional health authorities in the province to understand how different regulatory bodies may impact medicalization. In particular, research should focus its attention on the Northern Health Region, as this region comprises mainly Indigenous folks (72.5%) (Northern Health Report, 2022), who may have culturally distinct interpretations of 'home', 'family', and responsibility for older adults, and be more distrustful of Western medicine due to colonization (Geddes, 2017). As an Indigenous person, this is research I plan to conduct in the future, continuing with the auto-ethnographic methodology.

Additionally, it would be useful to investigate if the internalization of medicalized discourse by family/friend caregivers occurs in other provinces in Canada to the same extent. Manitoba is the only province which specifies in policy that recipients of care must have a back-up plan, and that home care services are not guaranteed. At the outset, this creates the expectation that family/friend caregivers will be involved in care and care decisions. However, without this expectation, further research could investigate whether caregivers in other provinces adopt similar roles and responsibilities voluntarily, or if differing provincial policies influence the extent to which they internalize medicalized understandings of care. A comparative, cross-provincial study could provide valuable insights into how policy environments shape caregiver

perceptions and could inform more equitable and supportive caregiving frameworks across Canada.

As a final reflection as a caregiver, I am incredibly grateful to the participants in this study. I was challenged to work through my own emotionally fraught experiences with the home care system, home care workers, and instances of iatrogenesis. While my journey to this sociologically informed research is complex, it ultimately enabled me to share the stories of other caregivers, with the hopes of making improvements in the system. It was comforting, yet disheartening, to hear that my experiences as a medicalized family member in a medicalized home were not unique. While providing care in the home can be an isolating experience, the sociological imagination (Mills, 1959) reminds us to see our personal troubles as rooted in broader systemic issues. Thus, in sharing my story and the voices of caregivers in this study, I hope to advise others that we need to create conditions that allow for the 'home' to remain in 'home care'.

Ultimately, in its current structure and organization in Manitoba, home care is not merely about healing, it is about regulation, normalization, and control. The extension of medical authority into the home highlights broader questions of power, autonomy, and governance, demonstrating that medicalization is not just about treating disease but about shaping the very fabric of everyday life. By applying Foucault's concepts of the medical gaze and biopower, this study provides a nuanced understanding of how medicalization and surveillance medicine operate within home care settings. The home is no longer a purely private space; it becomes a site of continuous medical oversight, where individuals are both the subjects and agents of medical surveillance. This transformation affects not only care recipients but also caregivers, reshaping their roles and relationships through the demands of medical expertise.

References

Allan, S., Roland, D., Malisauskaite, G., Jones, K., Baxter, K., Gridley, K., & Birks, Y. (2021). The influence of home care supply on delayed discharges from hospital in England. *BMC Health Services Research, 21*, 1297-1308. doi:https://doi.org/10.1186/s12913-021-07206-5

Anderson, L. (2006). Analytic Autoethnography. *Journal of Contemporary Ethnography*, *35*(4), 373-295. https://doi.org/0.1177/0891241605280449

Angus, J., Kontos, P., Dyck, I., McKeever, P., Poland, B. (2005). The personal significance of home: habitus and the experience of receiving long-term home care. *Sociol Health Illn*, *27*(2), 161-187.

Armstrong, D. (1993). Public Health Spaces and the Fabrication of Identity. *Sociology 27*(3), 393-410. https://doi-org.uml.idm.oclc.org/10.1177/0038038593027003004

Armstrong, D. (1995). The rise of medical surveillance *Sociology of Health and Illness*, *17*(3), 393-404. https://doi-org.uml.idm.oclc.org/10.1111/1467-9566.ep10933329

Armstrong, D. (2009). Commentary: Indeterminate sick-men--a commentary on Jewson's 'disappearance of the sick-man from medical cosmology'. *Int J Epidemiol*, *38*(3), 642-645. https://doi.org/10.1093/ije/dyp184

Armstrong, H., Armstrong, P., Coburn, D. (2001). *Unhealthy times political economy perspectives on health and care*. Oxford University Press.

Armstrong, P., Armstrong, H. (2005). Public and private: implications for care work. *The Sociological Review*, *53*, 167-187.

Aronson, J. (2006). Silenced complaints, suppressed expectations: The cumulative effects of home care rationing *International Journal of Health Services*, *36*(3), 535-556.

Arras, J. D., Neveloff Dubler, N. (1994). Bringing the hospital home: ethical and social implications of high-tech home care. *The Hastings Center Report*, *24*(5), S19+.

Ayo, N. (2012). Understanding health promotion in a neoliberal climate and the making of health conscious citizens. *Critical Public Health*, *22*(1), 99-105. https://doi.org/10.1080/09581596.2010.520692

Bates, A. P. (1964). Privacy- a useful concept? *Social Forces*, *42*(4), 429-436. https://doi.org/https://doi.org/10.2307/2574985

Bedini, L. A., Labban, J. D., Gladwell, N. J., & Dudley, W. N. (2018). The effects of leisure on stress and health of family caregivers. *International Journal of Stress Management*, *25*(S1), 43-55. https://doi.org/10.1037/str0000072

Benzein, E., Johansson, B., Saveman, B. (2018). Families in home care – a resource or a burden? District nurses' beliefs. *Community Nursing 13*, 867-875. https://doi.org/https://doi-org.uml.idm.oclc.org/10.1111/j.1365-2702.2004.01024.x

Berger, P., Luckman, T. (1967). *The Social Construction of Reality*. Double Day.

Bischoping, K., Gazso, A. (2016). *Analyzing the Talk in the Social Sciences: Narrative Conversation & Discourse Strategies*. Sage.

Bjornsdottir, K. (2009). The ethics and politics of home care. *Int J Nurs Stud*, *46*(5), 732-739. https://doi.org/10.1016/j.ijnurstu.2008.10.014

Bjornsdottir, K. (2018). 'Holding on to life': An ethnographic study of living well at home in old age. *Nurs Inq*, *25*(2), e12228. https://doi.org/10.1111/nin.12228

Blais, R., Sears, N. A., Doran, D., Baker, G. R., Macdonald, M., Mitchell, L., & Thales, S. (2013). Assessing adverse events among home care clients in three Canadian provinces using chart review. *BMJ Qual Saf*, *22*(12), 989-997. https://doi.org/10.1136/bmjqs-2013-002039

Boccagni, P., & Kusenbach, M. (2020). For a comparative sociology of home: Relationships, cultures, structures. *Current Sociology*, *68*(5), 595-606. https://doi.org/10.1177/0011392120927776

Bookman, A., Kimbrel, D. Families and elder care in the twenty-first century. *The Future of Children 21*(2), 117-140. https://doi.org/https://doi.org/10.1353/foc.2011.0018

Brady, M. (2014). Ethnographies of neoliberal governmentalities: From the neoliberal apparatus to neoliberalism and governmental assemblages. *Foucault Studies*, *18*, 11-33.

Bryman, A. (2004). *Social Research Methods* (Second ed.). Oxford University Press.

Buscher, A., Astedt-Kurki, P., Paavilainen, E., & Schnepp, W. (2011). Negotiations about helpfulness--the relationship between formal and informal care in home care arrangements. *Scand J Caring Sci*, *25*(4), 706-715. https://doi.org/10.1111/j.1471-6712.2011.00881.x

Buse, C., Twigg, J. (2014). Looking ‘‘out of place’’: analysing the spatial and symbolic meanings of dementia care settings through dress. *International Journal of Ageing and Later Life*, *9*(1), 69-95. https://doi.org/10.3384/ijal.1652-8670.14238

Busfield, J. (2017). The concept of medicalisation reassessed. *Sociol Health Illn*, *39*(5), 759-774. https://doi.org/10.1111/1467-9566.12538

Butz, D., Besio, K. (2009). Autoethnography. *Geography Compass*, *3*(5), 1660-1674. https://doi.org/10.1111/j.1749-8198.2009.00279.x

Campbell-Enns, H. J., Campbell, M., Rieger, K. L., Thompson, G. N., & Doupe, M. B. (2020). No Other Safe Care Option: Nursing Home Admission as a Last Resort Strategy. *Gerontologist*, *60*(8), 1504-1514. https://doi.org/10.1093/geront/gnaa077

Ceci, C., & Purkis, M. E. (2009). Bridging gaps in risk discourse: home care case management and client choices. *Sociol Health Illn*, *31*(2), 201-214. https://doi.org/10.1111/j.1467-9566.2008.01127.x

Ceci, C., & Purkis, M. E. (2011). Means without ends: justifying supportive home care for frail older people in Canada, 1990-2010. *Sociology of Health and Illness, 33*(7), 1066-1080. doi:doi: 10.1111/j.1467-9566.2011.01344.x

Chappell, N. L., Hollander, M. J. (2005). Family Caregivers: Increasing Demands in the Context of 21st-century Globalization? In *The Cambridge Handbook of Age and Ageing* (pp. 455-462). Cambridge University Press. https://doi.org/https://doi.org/10.1017/CBO9780511610714.048

Chappell, N. L., Hollander, M. J. (2011). An Evidence-Based Policy Prescription for an Aging Population. *Healthcare Papers*, *11*(1), 8-18. https://doi.org/https://doi.org/10.12927/hcpap.2011.22246

Clarke, V., & Braun, V. (2016). Thematic Analysis. *The Journal of Positive Psychology, 12*(3), 297-298. doi:https://doi.org/10.1080/17439760.2016.1262613

Collopy, B., Dubler, N., Zuckerman, C. (1990). The Ethics of Home Care: Autonomy and Accommodation. *The Hastings Center Report*, *20*(2), 1-16. https://doi.org/https://doi.org/10.2307/3562626

Conrad, P. (1992). Medicalization and Social Control. *Annual Review of Sociology*, *18*(1), 209-232. https://doi.org/https://doi.org/10.1146/annurev.so.18.080192.001233

Conrad, P. (2007). *The medicalization of society : on the transformation of human conditions into treatable disorders* Johns Hopkins University Press.

Conrad, P. (2013). Medicalization: Changing Contours, Characteristics, and Contexts. In *Medical Sociology on the Move* (pp. 195-214). https://doi.org/10.1007/978-94-007-6193-3_10

Conrad, P., Leiter, V. (2004). Medicalization, markets and consumers. *Journal of Health and Social Behavior*, *45*(Extra), 158-176.

Cooper, J., Urquhart, C. (2005). The information needs and information-seeking behaviours of home-care workers and clients receiving home care. *Health Information and Libraries Journal*, *22*, 107-116.

Coulourides Kogan, A., Wilber, K., Mosqueda, L. (2015). Person-Centered Care for Older Adults with Chronic Conditions and Functional Impairment: A Systematic Literature Review. *The American Geriatrics Society*, *64*(1), e1-e7.

Cross, A. J., Garip, G., & Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. *Psychological Health, 33*, 1321-1342.

Dalmer, N. K. (2019). A logic of choice: Problematizing the documentary reality of Canadian aging in place policies. *J Aging Stud*, *48*, 40-49. https://doi.org/10.1016/j.jaging.2019.01.002

Davidson, R. D. (2015). *Rhetorical Lessons in Advocacy and Shared Responsibility: Family Metaphors and Definitions of Crisis and Care in Unpaid Family Caregiving Advocacy Rhetoric.* University of Wisconsin, Milwaukee

Dean, M. (1999). *Governmentality: Power and Rule in Modern Society*. London: SAGE Publications

Denzin, N. K., Lincoln, Y.S. (2018). *The Sage handbook of qualitative research*. Sage.

Di Matteo, L., & Emery, H. (2015). Common Provincial Determinants and Cost Drivers. In G. P. Marchildon, & L. Di Matteo, *Bending the Cost Curve in Health Care: Canada's Provinces in International Perspective* (pp. 87-112). Toronto: University of Toronto Press.

Dubbin, L. A., Chang, J. S., & Shim, J. K. (2013). Cultural health capital and the interactional dynamics of patient-centered care. *Soc Sci Med*, *93*, 113-120. https://doi.org/10.1016/j.socscimed.2013.06.014

Dyck, I., Kontos, P., Angus, J., & McKeever, P. (2005). The home as a site for long-term care: meanings and management of bodies and spaces. *Health Place*, *11*(2), 173-185. https://doi.org/10.1016/j.healthplace.2004.06.001

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing Ethnographic Fieldnotes*. The University of Chicago Press.

England, K., & Dyck, I. (2011). Managing the body work of home care. *Sociol Health Illn*, *33*(2), 206-219. https://doi.org/10.1111/j.1467-9566.2010.01331.x

Esterberg, K. G. (2002). *Qualitative Methods in Social Research*. McGraw Hill.

Fierlbeck, K. (2011). *Health Care in Canada: A Citizen's Guide to Policy and Politics*. University of Toronto Press.

Fjelltun, A.-M. S., Henriksen, N., Norberg, A., Gilje, F., & Normann, H. K. (2009). Carers' Experiences with Overnight Respite Care. A Qualitative Study. *Vård i Norden*, *29*(3), 23-27. https://doi.org/https://doi.org/10.1177/010740830902900306

Forbat, L., & Henderson, J. (2005). Theoretical and Practical Reflections on Sharing Transcripts with Participants *Qualitative Health Research*, *15*(8), 1114-1128.

Forbes, D. A., & Edge, D. S. (2009). Canadian home care policy and practice in rural and remote settings: challenges and solutions. *J Agromedicine*, *14*(2), 119-124. https://doi.org/10.1080/10599240902724135

Forbes, D. A., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D., Henderson, S., Leipert, B., & Jansen, S. L. (2008). Availability and acceptability of Canadian home and community-based services: perspectives of family caregivers of persons with dementia. *Home Health Care Serv Q*, *27*(2), 75-99. https://doi.org/10.1080/01621420802022548

Foucault, M. (1975). *Birth of the Clinic: An Archaeology of Medical Perception* Vintage.

Foucault, M. (1977). *Discipline and Punish: The Birth of the Prison.* London : Allen Lane

Foucault, M. (1978). *The History of Sexuality* Éditions Gallimard.

Foucault, M. (1982). The Subject and Power. Afterword to H. Dreyfus and P. Rabinow. In P. R. H. Dreyfus, *Michel Foucault: Beyond Structuralism and Hermeneutics* (pp. 208-227). Chicago: University of Chicago Press.

Foucault, M. (1988). Technologies of the Self. In L. H. Martin, H. Gutman, & P. H. Hutton, *Technologies of the Self* (pp. 16-49). London: Tavistock.

Foucault, M. (1997). *Ethics: Essential Works 1954-1984*. Penguin.

Foucault, M. (2007). *Security, Territory, Population: Lectures at the College de France 1977-78*. Palgrave Macmillion.

Foucault, M. (2008). *The Birth of Biopolitics: Lectures at the College de France 1978-79*. Palgrave Macmillion.

Freund, P. E., McGuire, M. B., & Podhurst, L. S. (2003). *Health, Illness, and the Social Body: A Critical Sociology.* Saddle River: Prentice Hall.

Fries, C. J. (2009). Bourdieu's Reflexive Sociology as a Theoretical Basis for Mixed Methods Research: An Application to Complimentary an Alternative Medicine. *Journal of Mixed Methods Research, 3*(4), 326-348

Fries, C. J. (2014). Governing the health of the hybrid self: Integrative medicine, neoliberalism, and the shifting biopolitics of subjectivity. *Health Sociology Review*, *17*(4), 353-367. https://doi.org/10.5172/hesr.451.17.4.353

Fries, C. J. (2008). Older adults' use of complementary and alternative medical therapies to resist biomedicalization of aging. *J Aging Stud*, *28*, 1-10. https://doi.org/10.1016/j.jaging.2013.11.001

Fries, C. J. (2020). The Medicalization of Cancer as Socially Constructed and Culturally Negotiated. *Health Promotion International, 35*(6), 1543-1550.

Funk, L. (2012a). *Manitoba caregiver consultation final report*. Ministry of Healthy Living. Seniors and Healthy Aging Secretariat, Seniors and Consumer Affairs. https://www.gov.mb.ca/seniors/docs/caregiver_report.pdf

Funk, L. (2012b). Shared Responsibility? Family caregivers and home care nurses. *Canadian Nurse (1924)*, *108*(6), 52-52.

Funk, L. (2013). Home Healthcare and Family Responsibility:

A Critical Discourse Analysis of Talk and Text. *Healthcare Policy*, *10*(9), 86-97.

Funk, L. M. (2019). *Relieving the Burden of Navigating Health and Social Services for Older Adults and Caregiving* (Faces of Aging, Issue.

Funk, L. M., & Hounslow, W. (2019). The emotional landscape of accessing and navigating formal supports for older adults in one Western Canadian city. *International Journal of Care and Caring*, *3*(4), 531-548. https://doi.org/10.1332/239788219x15622471468519

Funk, L., Kuryk, K., Spring, L., & Keefe, J. (2024). Problematizing Dominant Assumptions about Unpaid Support through Exploring Case Study Profiles of Older Home Care Clients. *Health & Social Care in the Community*, *2024*, 3707796. https://doi.org/10.1155/2024/3707796

Funk, L. M., Penner, J. P., Dansereau, L., Kuryk, K. (2021). *Caregiving during COVID in Manitoba: Report of survey findings.* University of Manitoba

Furedi, F. (2004). *Therapy culture : cultivating vulnerability in an uncertain age*. Routledge

Gallie, W. B. (1955). Essentially contested concepts. *Proceedings of the Aristotelian Society, 56,* 167-198. https://doi.org/10.1093/aristotelian/56.1.167

Geddes, G. (2017). *Medicine Unbundled.* Toronto: Heritage House Publishing Company.

Glasdam, S., Henriksen, N., Kjaer, L., & Praestegaard, J. (2013). Client involvement in home care practice: a relational sociological perspective. *Nurs Inq*, *20*(4), 329-340. https://doi.org/10.1111/nin.12016

Glover, J. J., & Harman, A. (2000). The Myth of Home and the Medicalization of the Care of the Elderly. *The Journal of Clinical Ethics, 11*(4), 318-322.

Goodrich, K., Kaambwa, B., & Al-Janabi, H. (2012). The inclusion of informal care in applied economic evaluation: a review. *Value Health*, *15*(6), 975-981. https://doi.org/10.1016/j.jval.2012.05.009

Government of Canada. (2015). *When work and caregiving collide: How employers can support their employees who are caregivers – Report from the employer panel for caregivers.*

Retrieved from http://www.nationalseniorsstrategy.ca/wp-content/uploads/2015/03/When-Work-and-Caregiving-Collide.pdf

Government of Canada. (2019, March 28). *The new Canada Caregiver Credit*. Retrieved from Deductions, Credits and Expenses: https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/canada-caregiver-amount.html

Government of Manitoba. (2016). *Caregiver Recognition Act Report, for the period 2013-2015.* Winnipeg: Manitoba Health, Healthy Living, and Seniors.

Government of Manitoba. (2017, July). *Your Guide to Manitoba Home Care Services.* Retrieved from Seniors, Health and Active Living: https://www.gov.mb.ca/health/homecare/guide.pdf

Government of Manitoba. (2018a, December 11). *Caregiving*. Retrieved from Seniors and Healthy Aging: https://www.manitoba.ca/seniors/caregiving.html

Government of Manitoba. (2018b, December 12). *Health System Transformation*. Retrieved from Health, Seniors and Active Living: https://www.gov.mb.ca/health/hst/

Government of Manitoba. (2018c). *Homecare Services in Manitoba*. Retrieved from Health, Seniors, and Active Living: https://www.gov.mb.ca/health/homecare/

Guberman, N., Lavoie, J. P., Blein, L., & Olazabal, I. (2012). Baby Boom caregivers: care in the age of individualization. *Gerontologist*, *52*(2), 210-218. https://doi.org/10.1093/geront/gnr140

Hale, B., Barrett, P., & Gauld, R. (2010). Space and Liminality In *The Age of Supported Independence* (pp. 29-43). Springer Netherlands. https://doi.org/https://doi.org/10.1007/978-90-481-8814-7_3

Hango, D. (2020). *Support Received by Caregivers in Canada: Statistics Canada.* Retrieved from https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm#n1

Heaton, J. (1999). The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health and Illness*, *21*, 759-777.

Health Council of Canada (2012). *Seniors in need, caregivers in distress: What are the homecare priorities for seniors in Canada?* Retrieved from healthcouncilcanada.ca/files/HCC_HomeCare_FA.pdf

Hicks, E., Sims-Gould, J., Byrne, K., Khan, K. M., & Stolee, P. (2012). "She was a little bit unrealistic": Choice in healthcare decision making for older people. *Journal of Aging Studies*, *26*(2), 140-148. https://doi.org/10.1016/j.jaging.2011.10.004

Hill, M. (2009). Ways of seeing: using ethnography and Foucault's `toolkit' to view assessment practices differently. *Qualitative Research*, *9*(3), 309-330. https://doi.org/10.1177/1468794109105030

Hoefman, R. J., van Exel, J., & Brouwer, W. (2013). How to include informal care in economic evaluations. *Pharmacoeconomics*, *31*(12), 1105-1119. https://doi.org/10.1007/s40273-013-0104-z

Hook, D. (2001). Discourse, Knowledge, Materiality, History: Foucault and Discourse Analysis. *Theory and Psychology*, *11*(4), 521-547.

Illich, I. (1976). *Medical Nemesis: The Medical Expropriation of Health.* New York: Pantheon Books

IPSOS, C. M. A. (2019). *Canadians are nervous about the future of the health system*.

Jacobson, K. (2009). A developed nature: a phenomenological account of the experience of home. *Continental Philosophy Review*, *42*(3), 355-373. https://doi.org/10.1007/s11007-009-9113-1

Jewson, N. D. (2009). The disappearance of the sick-man from medical cosmology, 1770-1870. *Int J Epidemiol*, *38*(3), 622-633. https://doi.org/10.1093/ije/dyp180

Johnson, S., Bacsu, J., Abeykoon, H., McIntosh, T., Jeffery, B., & Novik, N. (2018). No Place Like Home: A Systematic Review of Home Care for Older Adults in Canada. *Can J Aging*, *37*(4), 400-419. https://doi.org/10.1017/S0714980818000375

Kawulich, B. B. (2005). Particiant Observation as a Data Collection Method. *Forum: Qualitative Social Research*, *6*(2), 1-28.

Keating, N. (2022). A research framework for the United Nations Decade of Healthy Ageing (2021-2030). *European Journal of Ageing, 19*, 775-787. doi:https://doi.org/10.1007/s10433-021-00679-7

Keefe, J. (2011). Supporting Caregivers and Caregiving in an Aging Canada. *IRPP Study*, *23*, 1-31.

Kendall, G., & Wickham, G. (1999). *Using Foucault's methods*. Sage Publications.

Khan, T. H., & MacEachen, E. (2021). Foucauldian Discourse Analysis: Moving Beyond a Social Constructionist Analytic. *International Journal of Qualitative Methods*, *20*. https://doi.org/10.1177/16094069211018009

Khayatzadeh-Mahani, A., & Leslie, M. (2018). Policies supporting informal caregivers across Canada: a scoping review protocol. *BMJ Open*, *8*(6), e019220. https://doi.org/10.1136/bmjopen-2017-019220

Koren, M. J. (2010). Person-Centered Care for Nursing Home Residents: The Culture-Change Movement. *Health Affairs*, *29*(2), 1-6.

Kuryk, K., Funk, L. M., Warner, G., Macdonald, M., Lobchuk, M., Rempel, J., Spring, L., & Keefe, J. (2023). Ageing in place with non-medical home support services need not translate into dependence. *Ageing and Society*, 1-26. https://doi.org/10.1017/s0144686x23000478

Leiknes, I., & Høye, S. (2012). Family caregivers experiences of provided home care to persons with Parkinsons disease. *Nordisk sygeplejeforskning*, *2*(1), 29-44. https://doi.org/10.18261/ISSN1892-2686-2012-01-04 ER

Lilly, M. B., Robinson, C. A., Holtzman, S., & Bottorff, J. L. (2012). Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. *Health Soc Care Community*, *20*(1), 103-112. https://doi.org/10.1111/j.1365-2524.2011.01025.x

Lindahl, B., Liden, E., & Lindblad, B. M. (2011). A meta-synthesis describing the relationships between patients, informal caregivers and health professionals in home-care settings. *J Clin Nurs*, *20*(3-4), 454-463. https://doi.org/10.1111/j.1365-2702.2009.03008.x

Lowy, I. (1988). Ludwik Fleck on the social construction of medical knowledge. *Sociology of Health and Illness*, *10*(2), 133-155. https://doi.org/https://doi.org/10.1111/1467-9566.ep11435448

Lynch, R. A. (2014). The politics of health in the eighteenth century. *Foucault Studies 18*, 113-127.

Mallett, S. (2004). Understanding home: A crtical review of the literature. *The Sociological Review, 52(1),* 62-89. https://doi.org/10.1111/j.1467-954X.2004.00442.x

Martin-Matthews, A. (2016). Situating 'Home' at the Nexus of the Public and Private Spheres. *Current Sociology*, *55*(2), 229-249. https://doi.org/10.1177/0011392107073305

McDonald, J., McKinlay, E., Keeling, S., & Levack, W. (2016). Becoming an expert carer: the process of family carers learning to manage technical health procedures at home. *Journal of Advanced Nursing, 72*(9), 2173-2184. doi:doi: 10.1111/jan.12984

McWilliam, C. L., Vingilis, E., Ward-Griffin, C., Higuchi, K., Stewart, M., Mantler, T., Gao, R., South West Community Care Access Centre Collaborative, G., & Champlain Community Care Access Centre Collaborative, G. (2014). An evaluation of the effectiveness of engaging Canadian clients as partners in in-home care. *Health Soc Care Community*, *22*(2), 210-224. https://doi.org/10.1111/hsc.12082

Meers, J. (2023). 'Home' as an essentially contested concept and why this matters. *Housing Studies, 38(4),* 597-614. https://doi.org/10.1080/02673037.2021.1893281

Mills, C. W. (1959). *The Sociological Imagination.* Oxford University Press.

Molony, S. L., McDonald, D. D., & Palmisano-Mills, C. (2007). Psychometric testing of an instrument to measure the experience of home. *Res Nurs Health*, *30*(5), 518-530. https://doi.org/10.1002/nur.20210

Mong, S. N. (2020). *Taking Care of Our Own: When Family Caregivers Do Medical Work*. Cornell University Press.

Montgomery, R. J. (1999). The Family Role in the Context of Long-Term Care. *Journal of Aging and Health*, *11*(3), 383-416. https://doi.org/https://doi-org.uml.idm.oclc.org/10.1177/089826439901100307

Northern Health Region. (2022). *Annual Report 2021-22.* Flin Flon: Northern Health Region

Pacheco-Vega, R. (2019). Writing Field Notes and Using Them to Prompt Scholarly Writing. *International Journal of Qualitative Methods*, *18*, 1-2.

Palęcka, A. (2023). Who cares for carers? Responsibilization and the discourse of self-care in health and social care literature during the COVID-19 pandemic. A critical review. *Qualitative Social Work*, *23*(6), 1025-1040. https://doi-org.uml.idm.oclc.org/10.1177/14733250231204628

Paradis, E., Liew, W., Leslie, M. (2019). Embodied spatial practices and the power to care. In N. Boero, Mason, K. (Ed.), *Oxford University Handbook of the Sociology of the Body* (pp. 1-25). Oxford University Press.

Parrott, R., Burgoon, J. K., Burgoon, M., & LePoire, B. A. . (1989). Privacy between physicians and patients: More than a matter of confidentiality. *Soc Sci Med*, *29*(12), 1381-1385. https://doi.org/https://doi.org/10.1016/0277-9536(89)90239-6

Pasveer, B., Synnes, O., Moser, I. . (2020). *Ways of Home Making in Care for Later Life*. Palgrave MacMillan. http://www.palgrave.com/gp/series/14875

Penney, L. (2013). The Uncertain Bodies and Spaces of Aging in Place. *Anthropology & Aging Quarterly 34*(3), 113-125.

Petro-Canada CareMakers Foundation. (2021). *Caregiving in Canada: Challenges and opportunities shaping a national conversation.*

Public Health Agency of Canada. (2019). *A Dementia Strategy for Canada*

Rabig, K., Kane, R., & Cutler, L. (2008). Deinstitutionalization: Shifting the Nursing Home Paradigm to Home. *The Gerontologist, 48*, 705-.

RANQ. (2020). *Informal caregivers: exhausted and impoverished by the pandemic*. https://ranq.qc.ca/wp-content/uploads/2020/08/RANQ-survey-pandemic-consequences-August2020.pdf

Raphael, D., Bryant, T., Mikkonen, J., Raphael, A. (2020). *Social Determinants of Health: The Canadian Facts*. York University School of Health Policy Management

Ricard, N. (2015). *Manitoba Home Care Program*. H. L. a. S. W. R. H. A. S. H.-S. S. Department of Health.

Rose, N. (1998). *Inventing Our Selves: Psychology, Power, and Personhood.* Cambridge: Cambridge University Press.

Rose, N. (2007). *The Politics of Life Itself: Biomedicine, Power and Subjectivity in the Twenty-First Century.* Princeton, NJ: Princeton University Press.

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: a reappraisal from population-based studies. *The Gerontologist, 55*, 309-319.

Roos, N. P., Havens, B. (1991). Predictors of successful aging: A twelve-year study of Manitoba elderly. *American Journal of Public Health*, *81*(1), 63-68. https://doi.org/https://doi.org/10.2105/AJPH.81.1.63

Rubinstein, R. L., & de Medeiros, K. (2015). "Successful Aging," Gerontological Theory and Neoliberalism: A Qualitative Critique. *The Gerontologist, 55*(1), 34-42. doi:doi.org/10.1093/geront/gnu080

Santos, S. C., Parnell, R., Kanon, H. A., Pattinson, E., Pitsikali, A., Sarhan, H. (2024). Blurred borders: Negotiating copresence in the family home through spatio-temporal strategies

for increased adult well-being. *Home Cultures, 21(2-3).* 159-183. https://doi.org/10.1080/17406315.2025.2454179

Schirato, T., Danaher, G., Webb, J. (2012). *Understanding Foucault: A Critical Introduction* (2nd ed.). Sage.

Schrecker T., B. C. (2015). Austerity: How Politics Has Pulled Away Our Safety Net. In *How Politics Makes Us Sick*. Palgrave Macmillan. https://doi.org/https://doi.org/10.1057/9781137463074_4

Seaman, A. T. (2018). The consequence of "doing nothing": Family caregiving for Alzheimer's disease as non-action in the US. *Soc Sci Med*, *197*, 63-70. https://doi.org/10.1016/j.socscimed.2017.12.001

Segall, A., Chappell, N. L. (2000). *Health and health care in Canada* Prentice Hall.

Segall, A., & Fries, C. J. (2017). Medicalizing Beings and Bodies: The Link between Population Health and Biomedical Care. In *Pursuing Health and Wellness: Healthy Societies, Healthy People* (pp. 313-376). Oxford University Press.

Shaffir, W. (1999). Doing Ethnography: Reflections on Finding Your Way. *Journal of Contemporary Ethnography*, *28*(6), 676-686.

Shafir, A., Garrigues, S. K., Schenker, Y., Leff, B., Neil, J., & Ritchie, C. (2016). Homebound Patient and Caregiver Perceptions of Quality of Care in Home-Based Primary Care: A Qualitative Study. *J Am Geriatr Soc*, *64*(8), 1622-1627. https://doi.org/10.1111/jgs.14244

Silver, H. J., & Wellman, N. S. (2002). Family caregiver training is needed to improve outcomes for older adults using home care technologies. *Journal of the American Dietetic Association*, *102*(6), 831-836. https://doi.org/10.1016/s0002-8223(02)90185-9

Spring, L., Funk, L., Kuryk, K., Warner, G., Macdonald, M., Burke, R., & Keefe, J. M. (2024). Person-Centered Home Care: Exploring Worker-Client Relationships Using an Intersectional and Critical Disability Framework. *J Appl Gerontol*, *43*(1), 101-109. https://doi.org/10.1177/07334648231201837

Spring, L., Kuryk, K., Mason, S., O'Neil, K., Keefe, J., (forthcoming). How Medical Objects, Meal Prep Assistance and Relational Culture Impact the Meaning of "Home" for Home Care Clients

Stall, N. (2019). We should care more about caregivers. *Canadian Medical Association Journal, 191*(9), E245-E246.

Stall, N. M., Campbell, A., Reddy, M., & Rochon, P. A. (2019). Words matter: the language of family caregiving. *Journal of American Geriatrics Society, 67*(10), 2008-2010.

Statistics Canada. (June 24, 2024). *Population Projections for Canada (2023-2073), Provinces and Territories (2023-2048).* Retrieved from https://www150.statcan.gc.ca/n1/pub/91-520-x/91-520-x2024001-eng.htm

Statistics Canada. (2020). *The Daily-Caregivers in Canada, 2018.* Retrieved from https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm

Statistics Canada (August 16, 2022). Home care use and unmet home care needs in Canada, 2021. https://www150.statcan.gc.ca/n1/daily-quotidien/220826/dq220826a-eng.htm

Sullivan, T. J., & Baranek, P. M. (2002). *First do no harm making sense of Canadian health reform*. Malcolm Lester.

Tamm, M. (1999). What does a home mean and when does it cease to be a home? Home as a setting for rehabilitation and care. *Disabil Rehabil*, *21*(2), 49-55. https://doi.org/10.1080/096382899297963

The Change Foundation. (2019). *Spotlight on Ontario's Caregivers Report 2019.* Retrieved from https://changefoundation.ca/spotlight-on-caregivers-report/

Toews, R. (2016). *Future of Home Care Services in Manitoba* S. a. A. L. Minister of Health.

Tracy, S. (2010). Qualitative Quality: Eight 'big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837-851.

Turner, B. (1987). *Medical power and social knowledge.* Sage.

Twigg, J. (1999). The spatial ordering of care: Pubilc and private in bathing support at home. *Sociol Health Illn*, *21*(4), 381-400.

Twigg, J., Wolkowitz, C., Cohen, R. L., & Nettleton, S. (2011). Conceptualising body work in health and social care. *Sociol Health Illn*, *33*(2), 171-188. https://doi.org/10.1111/j.1467-9566.2010.01323.x

Vanier Institute. (2017). *A snapshot of family caregiving and work in Canada.* Retrieved from http://vanierinstitute.ca/snapshot-family-caregiving-work-canada/

Watson, C. (2006). Unreliable narrators? Inconsistency (and some inconstancy) in interviews. *Qualitative Research*, *6*(3), 367-384.

Wiles, J. (2003). Informal caregivers' experiences of formal support in a changing context. *Health and Social Care in the Community*, *11*(3), 189-207.

Winslow, B. W. (2003). Family caregivers experiences with community services: A qualitative analysis. *Public Health Nursing*, *20*(5), 341-348. https://doi.org/https://doi.org/10.1046/j.1525-1446.2003.20502.x

Wolff, J., Boyd, C. (2015). A Look at Person-Centered and Family-Centered Care Among Older Adults: Results from a National Survey. *Journal of General Internal Medicine*, *30*(10), 1497-1504.

World Health Organization. (2021) *Decade of healthy ageing: Plan of action 2021-2030* https://cdn.who.int/media/docs/default-source/decade-of-healthy-ageing/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc_28

Wuest, J. (1995). Feminist Grounded Theory: An Exploration of the Congruency and Tensions Between Two Traditions in Knowledge Discovery. *Qualitative Health Research*, *5*(1), 125-137.

Appendix

1.0 Interview Guide

Socio-Demographic Cover Sheet and Question Guide for Live-in Caregivers

Before we begin the interview, I have some general questions about your background and identity.

Gender: M___ F___ Nonbinary____

Can you tell me about your relationship to [home care client]? Participant is client's:
_____

What is your age, in years? _____

What is [family member]'s primary condition for which they need your help?
_____

Are you employed? FT/PT/not at all/self-employed (how many hours per week)
_____

What is your type of occupation? (if applicable) _____

General place of employment? (if applicable) _____

What is the highest level of formal education that you have completed?

Elementary school or less____
Some high school____
High school graduate____
Some college (including CEGEP) or trade school____
Attended university____
University degree____

Post-graduate degree____

Other (please specify) _____

Considering your average annual NET household income, in which general category would you place yourself:

Below $19,999/year___

$20,000 - $39,999/year___

$40,000 – $59,999/year___

$60,000 - $79,000/year___

$80,000 - $99,999/year___

$100,000 or more___

Interview Question Guide for Live-in Caregivers[11]

Thank you for allowing me into your home today and agreeing to share your story with me. I want you to know that everything you say will be anonymized and kept confidential. I do not want this to feel like a job interview, but instead like a conversation. I am also a caregiver, and I was hoping we could share our stories together. I was a live-in caregiver for my Mom for about 10 years. I helped her get dressed in the mornings, take her pills, blend her meals, and get ready for bed at night. We had some changes to our home as well, such as removing our bathroom door, installing a wheelchair lift, and putting alarms and rails on her bed. Although I no longer live with her, I still provide care and have regular interactions with her home care workers.

I have a list of particular details that I would like to cover, but as much as possible, I'd like to keep this conversational. What's most important is that I hear your perspectives and experiences as a caregiver. Can I start by asking…

1. How long have you been a caregiver?
2. How many hours a week do you spend caring?
3. Please describe a typical day for you as a caregiver. What kind of tasks do you perform?
4. Could you share with me what "home" means to you?
    a. What does "family" mean to you?
    b. What does "home care" mean to you?
    c. And finally, what does the term "caregiver" mean to you?
    d. How, if at all, are these terms interrelated for you?
5. How many hours a week does your loved one receive care from home care? What kind of tasks does home care perform?
6. I know from my own experience caring for my mom that being a care provider often entails contact with other home care service providers (i.e. home care attendants, case coordinators, OT/PT, nurses, etc.)? Can you tell me about your experiences with other home care service providers?
7. Have you made adjustments to your home to receive home care services? (Who suggested the changes? Was there an assessment of changes that needed to be made?)

[11] These core questions may not always be asked in this order, depending on the flow of the participants' narrative. Also, these core questions might generate other follow-up clarifying questions or probes (such as "tell me more" or "how was that?"). The interviewer will avoid interjecting in participant responses or asking overly leading questions.

8. Can you think of any frustrations or disagreements that you've had with home care, or home care workers? What was this experience like? Have the issues been resolved?
9. In what ways has the relationship between you and the care recipient changed since receiving home care?
10. Do you provide medical care? If so, what kind? Did you receive training to provide medical care? What was the training like?
11. Finally, I would like to talk about the Caregiver Recognition Act of Manitoba that was legislated in 2011. Can we look at the 8 principles together and talk about what these may or may not mean to you? (See principles below)
12. Is there anything you would like to add?

Principles of Bill 42: *The Caregiver Recognition Act*[12]

1. The relationship between caregivers and the persons for whom they care should be recognized and respected.
2. The valuable social and economic contribution that caregivers make to society should be recognized and supported.
3. Caregivers should be acknowledged as individuals with their own needs within and beyond the caring role.
4. Caregivers should be supported to enjoy optimum health and social well-being and to participate in family, social and community life.
5. Caregivers should be considered as important contributors with other care providers in the provision of care, support or assistance, acknowledging the unique knowledge and experience of caregivers.
6. Caregivers should be treated with dignity and respect.
7. Caregivers should be supported to achieve greater economic well-being and sustainability and, where appropriate, should have opportunities to participate in employment and education.
8. Support for caregivers should be timely, responsive, appropriate and accessible.

[12] https://web2.gov.mb.ca/bills/39-5/b042e.php

2.0 Recruitment Materials

CALL FOR FAMILY/FRIEND CAREGIVERS OF HOMECARE RECIPIENTS TO PARTICIPATE IN INTERVIEWS FOR A RESEARCH STUDY:

LIVE-IN CAREGIVERS PERSPECTIVES ON THE PROVISION OF HOMECARE SERVICES IN MANITOBA

Do you live with an older adult who receives home care?
Do you live in Manitoba?
Are you 18 years or older?

Live-in caregivers are invited to participate in a study about your experiences providing care and how Home Care affects your life and home. Co-residing with someone who receives Home Care can create a unique space of both care and work.

I want to hear your story.

I hope the findings from this study will help me better understand the experience of Home Care from the perspective of live-in family caregivers.

Participation will involve a confidential one-on-one interview in your home lasting 1.5-2 hours and a small honorarium will be provided.

This research is being led by
Kaitlyn Kuryk (PI; Ph.D. Candidate) and Dr. Chrisopher Fries (Supervisor)

If you are interested, please contact Kaitlyn Kuryk at:

obedzink@myumanitoba.ca or

[redacted]

This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus, HE2022-0061. If you have concerns or complaints about this project, you may contact the above named persons or the Human Ethics Coordinator (HEC) at 474-7122 or humanethics@umanitoba.ca

University of Manitoba

3.0 List of Caregiver Resources

Seniors and Healthy Aging
Phone: 204-945-6565
Email: seniors@gov.mb.ca
Website: www.gov.mb.ca/seniors/
Offers information on seniors' programs and services across Manitoba for seniors, families, caregivers, and professionals.

Age and Opportunity
Phone: 204-956-6440
Email: info@ageopportunity.mb.ca
Website: https://www.aosupportservices.ca/
A & O Support Services for Older Adults is a not-for-profit social service agency that provides programs and services to older adults 55+ that support and enhance the physical, intellectual, emotional, social and spiritual lives of older persons. Offers safety and security, social inclusion, and counselling services.

Caregiving with Confidence
Phone: 204-452-9491
Email: volunteer@caregivingwithconfidence.org
Website: http://caregivingwithconfidence.org/
Caregiving with Confidence supports informal caregivers in Winnipeg

Carers Canada
Phone: 905-567-7373
Website: https://www.carerscanada.ca/partners/
Alliance of diverse organizations that seeks to support and recognize informal caregivers all across Canada.

Seniors Abuse Support Line
Toll Free: 1-888-896-7183
The 24 hour toll free Seniors Abuse Support Line is a confidential service for older adults who are experiencing abuse. It provides information, support and counseling. Abuse line staff can also help connect people to resources and support services available in the community.

The Protection for Persons in Care Office
Phone: 204-788-6366
Toll Free: 1-866-440-6366
TTY Winnipeg: 204-774-8618
TTY Toll Free: 1-800-855-0511
Email: protection@gov.mb.ca
Website: www.gov.mb.ca/health/protection
The Protection for Persons in Care Act is an extra safeguard built into Manitoba's health care system. This law is to help protect adults from abuse and neglect while receiving care in personal care homes, hospitals or any other designated health facility. The act requires that a service provider

(or other person) who has a reasonable basis to believe that a patient is, or is likely to be abused or neglected, shall promptly report the belief, and the information to the PPCO.

Health Links – Info Santé
Phone: 204-788-8200
Toll Free: 1-888-315-9257
Health Links – Info Santé is a province-wide program that offers triage services, health information and referral, and nurse advice to callers 24 hours a day, seven days a week in over 100 languages.

Crisis Response Centre
Located at 817 Bannatyne Avenue, **Winnipeg** MB
The Crisis Response Centre is open 24 hours a day, seven days a week. The centre offers walk-in assessment and treatment for those in mental crisis, along with referrals to other mental health services. The centre is also home to the Mobile Crisis Service for adults. To reach this team, call 204-940-1781.

Geriatric Mental Health Teams
Phone: 204-982-0140
Geriatric mental health teams assess individuals over the age of 65 years, living in **Winnipeg**. Anyone can refer to this service. Clients are seen by a geriatric mental health clinician in their home or in personal care homes for an assessment of mental health issues.