Caregiver Experiences with Publicly Funded and Privately Financed Home Care in Ontario

Alla Yakerson

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Abstract

Home care is an integral aspect of Ontario's health care system. Services provided to individuals may allow them to live with independence within the comfort of their own residence. Over the last decade the demand for home care has risen substantially due to a number of factors including: the growing population, the rising share of individuals over the age of 65, the increasing rates of complex and chronic conditions, trends to faster hospital discharge, and advances in treatments/technologies. Simultaneously, the rise in neoliberalism has led to the restructuring of financing and delivery of health care through market-based models. While ostensibly an attempt to reduce public spending, it is more likely a result of an ideological shift away from state-provided care towards market-oriented service provision. In light of this, in the home care area, the state has been able to reduce its financial obligations by enabling privatization in the sector. The significance of policy change in the home care system and the decisions regarding the balance of the public/private scheme, therefore, have had serious implication for the experiences of those who provide the care – the unpaid *Informal Family Caregivers* (IFC).

At present, public funding and provision of care have not kept up with the demand for services, thereby, encouraging individuals to turn to the private market if they find inadequacies in the delivery of publicly funded local home care services (McGregor, 2001). In light of this, the purpose of this study is to examine the lived experiences of IFC who seek services for their relatives from the public home care system as well as from the private marketplace. In doing so, the goal is to understand the circumstances and challenges faced by these caregivers in accessing care in each of these two systems and obtaining respite from their duties. This knowledge is fundamental to the health care system which seeks to prevent the institutionalization of

individuals as well as to minimize health care costs associated with the physical and psychological outcomes of caregiving which may differ in quality.

This study is influenced by the work of FP economists to explain inequities in health as stemming in part from the unequal division of labour in society by which women must both gain paid employment and carry out household work (cleaning, cooking, laundry, gardening, taking care of children and the elderly etc.). FPE further draws on the Social Determinants of Health (SDOH) concept, which considers how the organization, and distribution of resources such as income and health services interact with the social location of gender to impact health outcomes.

The qualitative research approach of descriptive phenomenology is employed to convey and understand the lived experiences of IFC with both the publicly funded and privately financed home care systems in and around the Greater Toronto Area. Quantitative analysis is further used to complement the voices of the participants.

By illuminating micro-level individual experiences in relation to broader political and economic context, the development of new theories can take place and lead to further investigations pertaining to the phenomenon of interest. By generating knowledge and creating awareness, the ultimate goal is to influence policies of care and service provision to address issues concerning equity and health.

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I dedicate this research to my great-grandmother and grandmother who always encouraged me to pursue higher education.

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Chapter One
Evolution of the Study

Introduction

Long Term Care (LTC) refers to ongoing, indefinite care for individuals who can no longer solely manage with activities of daily living. LTC services include those provided in individual's homes such as nursing care and personal support. In addition, LTC includes community support services such as meals-on-wheels, transportation, adult day programs such as community mental health, respite and supportive living programs, and institutional care at long-term care facilities (nursing homes). The focus of the present research is on the in-home services of the LTC system. More specifically, this study is aimed at understanding and illuminating the experiences of unpaid Informal Family Caregivers (IFC), with publicly funded as well as privately financed home care services in and around the Greater Toronto Area (GTA), within the last 36 months (2016-2018). These experiences are very much embedded in the context of the rise in neoliberalism, a market-oriented policy model, which has led many countries, including Canada, to restructure the financing and delivery of health care in an attempt to reduce public spending (England, Eakin, Gastaldo, & McKeever, 2007). This study illuminates the experiences of IFC in this broader context, revealing the ways in which reform policies such as decentralization, privatization and cost cutting, promote inequities in access to home care supports and ultimately health.

Overview of Home Care in Canada and Ontario

In Canada, The Canada Health Act (CHA) identifies the conditions and criteria to which individual provinces and territories must conform in order to receive funding for health care services (Madore, 2000). The act defines five national principles: public administration, comprehensiveness, universality, portability, and accessibility, to which jurisdictions must abide. However, these principles apply only to those services deemed strictly medically necessary such as activities in hospitals and primary care. LTC services which provide extended health care such as home care, are not subject to the principles of the Act and remain outside of universally insured healthcare (Madore, 2000). Consequently, there is no obligation on the federal or provincial governments to guarantee the provision of home care. This results in variations in the delivery, funding and distribution of these services across the country (Landry et al., 2008).

In 2004, the Canadian Home Care Association developed an inclusive definition of home care which is currently adopted throughout the country. Home care is "an array of services, provided in the home and community setting, that encompass health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the informal (family) caregiver" (Canadian Home Care Association, 2016). Home care services should be based on individual needs and provided to patients with health challenges including acute or chronic conditions, palliative patients, children/adults with disabilities or special needs, and the frail elderly. Services are provided by various professionals including Personal Support Workers (PSWs), physiotherapists, occupational therapists, dieticians, social workers, speech language pathologists, Registered Nurses (RNs) and Registered Practical Nurses (RPNs).

In Ontario, home care falls under the jurisdiction of the Ministry of Health and Long Term Care (MOHLTC). The MOHLTC funds 14 Local Health Integration Networks (LHINs) which contract with home care provider agencies for the actual delivery of care.

Diagram 1. provides a general overview of Ontario's healthcare funding structure in relation to the LHINs[1] and home care (Closing the Gap Healthcare, 2018).

Individuals requiring home care services may obtain them via the publicly funded system or privately, through direct out-of-pocket pay to a home care agency or independent service provider (e.g., PSW). On the public side, the LHINs cover the costs of the services (PSW, Nursing, etc.) delivered by a particular home care agency servicing the area of the residence. Referrals for publicly funded home care can be made via the hospital upon discharge, by the client's physician, or by calling the area's LHIN which then assesses the need, amount, and type of care required.

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[1] Recently, Ontario's newly elected Progressive Conservative Party proposed a bill to create a Super Agency, called *Ontario Health* by dissolving the 14 LHINs and merging their duties with other key agencies. As such, the funding structure of Ontario's healthcare will soon be amended. Refer to section on *Recent Developments in the Home Care Sector*.

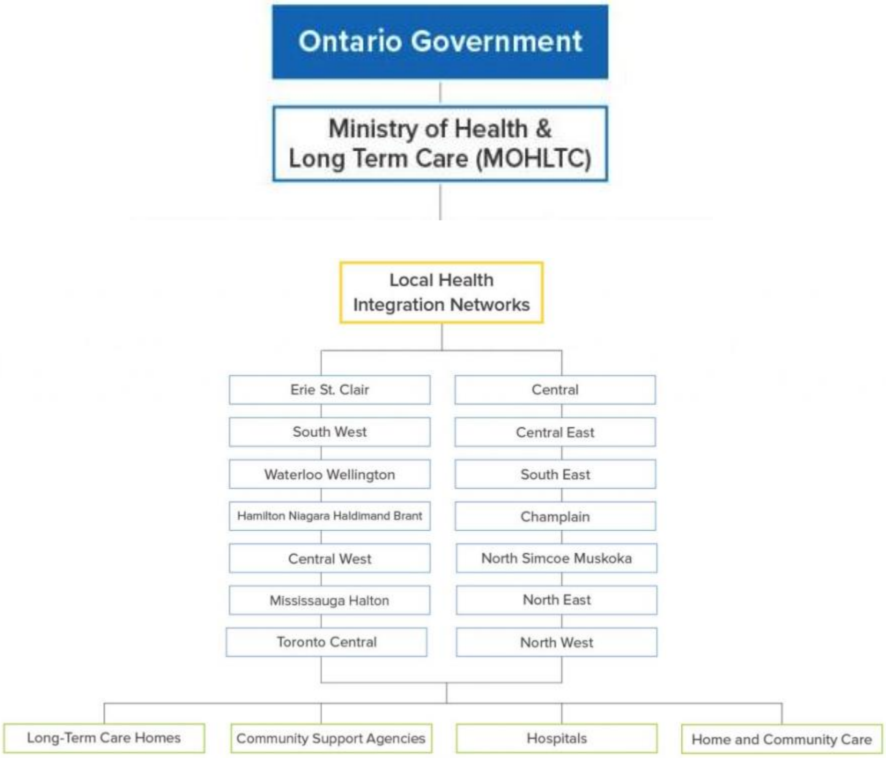

Diagram 1. Funding Structure

The actual classifications and distinguishing characteristics of public vs. private requires close examination. According to Starr (1988), public and private are typically paired to describe a number of related oppositions which can be depicted in the mind as – *public is to private as open is to closed*. Public often means governmental or official while private is characterized by what lies beyond the state's boundaries in the market or in the family.

Public can refer to semi-autonomous agencies, which are publicly funded but independently managed and accountable to public officials for particular outcomes (Baranek, 2000). *Private* is a broader category, and generally means the withdrawal from previously delegated public spheres or an annexation by an individual or a group of some good formerly available to all. Baranek (2000) further speaks of the existence of five private sectors in Ontario: corporate for-profit, small business/entrepreneurial, charitable/non-profit run by paid employees, charitable/non-profit run by volunteers, and family/personal supports. In the context of Ontario's home care system, all agencies are private and are either for-profit or non-profit organizations. Agencies which have contracts with the LHINs are considered semi-autonomous as they are publicly funded by the LHINs and accountable for the delivery of care.

According to Armstrong & Armstrong (2004), public and private have dual meaning. The first considers the divisions in the formal economy. That is, governmental supports/goods as public and for profit/non-profit organizations as private. The second distinguishes the overall formal economy (public) from the household which is private. In the context of home care, the first divide refers to publicly funded vs. privately financed home care supports, while the second differentiates the overall home care system from the household where the care is provided. Since state initiatives can influence any aspect of the divisions, IFC experiences must be considered within all of these environments.

The shift towards market mechanisms (neoliberalism) and the progressive retreat of the state, from the mid 1970s, marked a prominent decrease in public supports including those of healthcare, education and community services (Aronson & Neysmith, 1997; England, Eakin, Gastaldo, & McKeever, 2007). In the formal economy, the state pursued market oriented practices such as cuts to public service and privatization. The focus on cost-cutting together with advancements in technology and pharmaceuticals have thus, enabled a shift of medical care from hospital to the home setting. However, in the home, care services are not under the protection of the CHA and therefore not mandated to be publicly insured and delivered. In light of this, the state has been able to reduce their financial obligations, while at the same time enabling privatization in the sector. The significance of policy change and decisions regarding the balance of the public/private scheme, therefore, have had serious implication for the experiences of those who provide the care.

Phenomenon of Interest

The phenomenon to be explored is the lived experiences of IFC with publicly funded and privately financed home care services (PSW and/or nursing). The experience of informal caregiving is an ancient phenomenon. However, informal caregiving for an increasing number of frail elderly and those with disabilities, is a growing occurrence. This is the case since advances in medical technology of the twentieth century and an improved standard of living have resulted in longer life expectancy while at the same time increasing the likelihood of living with an illness or disability. Furthermore, the trends in hospital procedures have led to more individuals being discharged faster with acute and complex conditions requiring integrated home care services.

Considering the expenditures of care in Ontario, with a hospital bed costing $842.00/day, a Long-Term Care bed $126.00/day and care at home $42.00/day, the push to de-institutionalize care and shift health care services into the home setting by the MOHLTC appears to be reasonable (Home Care Ontario, 2017). At the same time, Ontario’s home care reform aimed at creating market competition between provider agencies with the intention of cost reduction and privatization has led to budget shortfalls, higher per-visit costs, and staffing shortages (England, Eakin, Gastaldo, & McKeever, 2007; Randall & Williams, 2006). This has resulted in decreased publicly funded home care services. These developments have the potential to have a tremendous impact on the lived experiences of IFC, who are primarily women and often must occupy both the public realm of the labour market and the private domain of the home (Armstrong & Armstrong, 2010; Brannen, 2006).

Informal caregiver distress is on the rise (Health Quality Ontario 2015; Health Quality Ontario, 2018). The shift in care from institution to home has increased both the number of individual seeking home care, as well as the intensity in the care they require (Health Quality Ontario, 2015). Most recent data indicate that 44% of informal caregivers supporting home care patients have feelings of distress, anger or depression. This is a 21% increase in a 2-year period (Health Quality Ontario, 2019). In addition, informal caregiver distress increases when supporting home care patients who present with higher care needs. Fifty six percent of individuals who look after family members with the poorest cognitive functioning, high dependence with activities of daily living, presence of behavioral issues and high frequency of falls, report caregiver distress (Health Quality Ontario, 2016).

Women most often take on the role of caregiving for their spouse, parent or child. Female spouses are usually older and dealing with their own health issues or else they are daughters having to both work for pay and respond to home demands. Women juggle being wives, mothers, workers, and unpaid caregivers. As a result, they typically occupy precarious employment, with stagnant wages and no benefits or job security (Messing & Ostlin, 2006). Such working conditions make it challenging to keep up with the high costs of living, especially in large cities such as the Greater Toronto Area (GTA) (Draaisma, 2018). Eventually, enduring the multiple roles of work and home, and struggling with financial difficulties, leads to physical burnout, emotional distress and negative health outcomes (Armstrong & Armstrong, 2010; Brannen, 2006; Doyal, 1995; Lee & Tang, 2015; Swanberg, 2006).

It should be noted that men also take on the role of caregiving. However, their experiences are considerably different than those of women. Male informal caregivers more often look after their frail or elderly spouses as opposed to their parents or children with disabilities (Chang & White-Means, 1991; Gallicchio et al. 2002; Lee & Tang, 2015). They tend to be healthier, have better overall quality of life, be more active in the labor market, and report less mental, physical, and financial stress than do female informal caregivers (Chang & White-Means, 1991; Brannen, 2006; Lee & Tang, 2015). In addition, men tend to spend significantly less time and engage in less personal care tasks then women carers (Brazil et al, 2009; Gerstel & Gallagher, 2001; Lee & Tang, 2015; Statistics Canada, 2012).

Research pertaining to the home care sector has primarily focused on the publicly funded system in order to measure distress, mental health and the overall quality of life of IFC (Cochrane, J. J., Goering, P. N., & Rogers, 1997; Cameron et al., 2006; Hirdes et al., 2012; Aronson, 1997). Very little research has focused on conducting direct interviews to understand the lived experiences of these caregivers with the publicly funded home care system. One such study was recently conducted by The Change Foundation and the Ontario Caregiver Coalition to better understand the experiences of informal caregivers pertaining to their interaction with the public home care system (The Change Foundation, 2016). The final report outlined a number of findings in the narratives of the informal caregivers including the difficulty in navigating the public home care system, the lack of communication with service providers, and the unmet needs for respite. (The Change Foundation, 2016).

Research has rarely examined IFC experiences with privately financed services. This could be due to the difficulty in enlisting busy and distressed caregivers for interviews. In addition, privately financed agencies may be reluctant to collaborate with researchers who can expose their inadequacies. Nevertheless, research about experiences with the public system give us clues as to why people seek private care for example, the difficulty in navigating the public system and the need for additional respite.

The present study evolved from the necessity to expand knowledge in the area of IFC experiences with home care services, as impacted by the broader political and economic context. On a personal level, my own experiences as a physiotherapist, having witnessed carers struggling in their roles, led to this particular topic of interest. On the whole, the primary aim of this research is to comprehensively explore the experiences of those seeking home care services publicly as well as additional care hours privately. The focus, specifically, is on the informal caregivers who are supporting *family* members as oppose to friends and neighbors.

Understanding how IFC come to access home care services in the first place, and the challenges they face in their day to day lives, can lead to further investigations regarding this phenomenon. Ultimately, the goal is to influence policies of care and service provision to address issues concerning equity and health.

Presentation of the Research Framework and Methods

The Feminist Political Economy (FPE) framework documents the impact of socio-economic policies on states, markets, and households (Armstrong, 1997; Armstrong & Armstrong, 2004; Armstrong & Armstrong, 2010; Aronson & Neysmith, 1997; Luxton & Bezanson, 2006). Examining these relationships allows for a contextual understanding of the experiences of women in the public realm of production and the private realm of household as pertaining to the provision of care. Thus, this study is influenced by the work of FP economists to account for the unique experiences of women in a highly gendered labour market as well as to highlight the undervalued, unpaid work of caregiving.

In the home care sector, the paid labour work force is primarily dominated by women. As such, the introduction of market-based health care reforms greatly impacts their working conditions and in turn, the delivery of services to clients (Aronson & Neysmith, 1997; England, Eakin, Gastaldo, & McKeever, 2007). Likewise, in the household, the unpaid work of caregiving is considered, for the most part, women's work (Armstrong, 1997; Armstrong & Armstrong, 2004; Armstrong & Armstrong, 2010; Aronson & Neysmith, 1997; Luxton & Bezanson, 2006). For women, the withdrawal of public social supports, and promotion of private market mechanisms constrain the conditions necessary for the provision of good/adequate care. Inequities in health, economic vulnerabilities and decreased standards of living emerge, especially for those carers who are made more vulnerable by their social conditions.

This study will also draw on the SDOH framework which considers how the organization, and distribution of SDOH such as gender, income, and health care services, impact health outcomes (Raphael, 2016). In this study, income is addressed because it influences the ability to purchase health care services, in this case, privately financed home care. Since the majority of IFC in the home care sector are women, a specific focus on gender is relevant. Finally, the social determinant of health care services (public and private home care) is addressed because variations in access result in differential health outcomes for users (IFC). This study does not include an analysis of age, race and class. Although these factors are important, the recruited participant sample characteristically allowed for the analysis of stories pertaining to gender and income. In order to further this analysis and include the intersection with other variables, future research will need to involve translation services, participants residing in poorer and wealthier areas of the GTA, participants of all ages including those in the sandwich generation and a larger sample size.

Prior to commencing the discussion on the chosen research methods, it is important to consider what is already known about the structure of the home care system in relation to IFC experiences and position it in the context of this study. By drawing on my personal experience as a physiotherapist as well as previous research (Grant & Church, 2015; England, Eakin, Gastaldo, & McKeever, 2007; Health Quality Ontario, 2015; The Change Foundation, 2016), I am able to present general hypotheses and expectations regarding possible findings. The interview questions presented in the next section are based on these hypotheses.

What is known about the current public home care system is that it is underfunded and understaffed. As such, when I embarked on this research, I expected that IFC would report challenges in obtaining sufficient service hours to meet the needs of the client (individual being cared for). I also expected to hear about potential cancellations/changes in service providers who are coming to see clients, due to the high job turnover in the sector. As a result, I believed that it is unlikely that IFC who look after individuals with high needs are able to have many opportunities for respite. In addition, I hypothesized that IFC looking after clients with high care needs, would not be able to maintain employment. I expected to hear about difficulties with physical (poor sleep, exhaustion) and psychological (anxiety/depression) functioning as well as financial struggles.

On the private funding side, I expected that financial resources would play a significant role in hiring additional care. As such, I expected there to be variations between the lives led by IFC in the public system vs. those turning to the private marketplace. Those who hire, may have more opportunities for respite and report fewer negative impacts on health. I expected those in the private category to be able to maintain employment and/or live separately from the client. This was assuming that a consistent care provider is obtained.

Research Questions

This study aims to illuminate the experiences of IFC in the broader context of neoliberal reforms which include the ways in which reform policies such as decentralization, privatization and cost cutting, promote inequities in access to home care supports which impact health. Below are the questions that guided my interviews with care providers in the public and private home care context.

Public

1. What does a caregiver’s typical day look like?
2. What are the reasons caregivers decide to seek public home care services?
3. What services are received? And how much?
4. What are the challenges in accessing public home care services?
5. What is the experience dealing with the public agencies and their providers?
6. What would caregivers like to see improved in their experience?
7. How many service hours do caregivers think they require or would like?
8. Once public services are initiated, do caregivers obtain the needed respite?
9. What are the unmet needs/personal challenges of caregivers?

Private

1. What does a caregiver’s typical day look like?

2. Do caregivers purchasing privately funded services use them to supplement those that are publicly available?
3. What are the reasons caregivers decide to seek private home care services?
4. How do caregivers choose a particular private home care agency/independent service provider?
5. What services are normally purchased? (nursing, Personal Support Worker (PSW), etc.) and how much?
6. What are the challenges in accessing private home care services (if any)?
7. What is the experience dealing with the private agencies and their providers?
8. What would caregivers like to see improved in their experience?
9. How many service hours do caregivers think they require or would like?
10. Once private services are initiated, do caregivers obtain the needed respite?
11. What are the unmet needs of caregivers?

This research utilizes a mixed-methods approach. The qualitative research approach of phenomenology is employed to convey and understand the lived experiences of IFC with the publicly funded and privately financed home care systems in and around the Greater Toronto Area (GTA). Although FPE and phenomenology are typically not paired for research purposes, the particular consideration for women’s unpaid caregiving work as described by the participants in accordance to their experiences, allows for this methodology/methods combination. As a philosophy, phenomenology is a particular technique of approaching the world and apprehending lived experience (Merleau Ponty, 1962). As a research method, phenomenology is a process of re-examining what Husserl (1962) termed *the things themselves*. Phenomenology is a descriptive, open, and flexible method allowing the researcher to deeply immerse themselves within the phenomenon under investigation (Vagle, 2014). Phenomenological inquiry is well-suited for understanding caregiver experiences, allowing for voices to be heard and meanings to be uncovered. During the process, the researcher's personal experience, beliefs, and knowing, are suspended or bracketed in order to wholesomely study the realities of the phenomenon as it is portrayed (Husserl, 1962). Strategies used for bracketing include being open to listening to the participants without interruption or interjection of the researcher's opinions, reflexive journaling, open-ended interview questioning and the exploration of a through literature review only after the interviews are completed.

In addition, this study employs a quantitative approach to analyze demographics and determine if there are significant relationships between particular variables. The quantitative findings may help explain and strengthen/complement what is heard from the voices of IFC (qualitative findings).

The findings in this study are organized in two main sections- quantitative and qualitative findings. Within each section the experiences of IFC with publicly funded and privately financed home care are discussed separately. Since this topic is under-researched, the separation into two groups, public and private, allows for a more wholesome analysis and can more clearly address the experiences of IFC with the different systems they are using. In addition, separating the findings enables an understanding of some of the differences in experiences within the two systems. It should be noted that some participants supplement publicly funded services with the purchase of additional hours privately from a home care agency (including those which also have contracts with the LHINs) or independent health service provider. The experiences of these participants are discussed in the privately financed home care section along with reasons for supplementation.

Relevance to Health Policy and Equity

Despite women's contribution to both the private realm of the household, and the public realm of production, only the latter is valued in society (Armstrong & Armstrong, 2010). There are numerous reasons for this phenomenon including the deliberate exclusion of household and care work from the System of National Accounts (SNA), the rise of neoliberalism, and the organization of power across institutions and social relations that privileges men over women in terms of rights and access to resources. By making care work invisible and unpaid, values such as compassion, duty and reciprocity are overlooked, in turn, lending well to the goals of cost saving in publicly funded services, privatization, and profit generation.

Home care is a sector which is sustained and depends primarily on the informal work of caregiving (Armstrong & Armstrong, 2010). Since this work is invisible, unpaid and is considered "natural" to women, there are few if any programs which provide financial compensation or other forms of support for their efforts. Within the home care sector, chronicled changes in reforms leading to budget deficits in publicly funded services, have placed an even greater load on IFC. Those individuals with adequate financial resources may have the opportunity to turn to the private marketplace in order to obtain respite from their duties. Consequently, differences in access to services, may result in health inequities between caregivers based on their socioeconomic status.

Overall, very little is known about the actual experiences of IFC. As such, this study is aimed at understanding the lived experiences of IFC who seek services from the public home care system as well as from the private marketplace. In doing so, the goal is to understand the circumstances and challenges faced by these individuals in accessing care and obtaining respite from their caregiving duties. This knowledge is important for improving the health care system which seeks to prevent individuals from being institutionalized as well as to minimize health care costs associated with the poor physical and psychological outcomes of caregiving.

Dissertation Outline

This chapter is followed by six additional chapters. Chapter 2, provides the definition and context of informal family caregiving in Ontario. Chapter 3, presents the review of literature pertaining to the political and historical context of home care in Ontario. Chapter 4, provides a description of the theoretical frameworks that inform this research. Chapter 5, outlines the methods and analytical tools employed in conducting this research. Chapter 6, presents the study findings and finally chapter 7, discusses the findings, implications, recommendations and limitations of this research.

Chapter Two
Caregiving

Definition of Caregiving

According to the Oxford English Dictionary (2010), caregiving is characterized by care and close attention to the needs of others, particularly those who have mental or physical disabilities or the elderly, who have lost the ability to function independently.

The term *caregiving* has been actively used and studied in a range of fields, in order to properly understand and acknowledge its existence in contemporary society. The definition of caregiving naturally contains elements associated with the act of *care and giving* by close relatives, friends or by trained health care professionals.

The verb *give* is derived from the Scandinavian word *giva* and an Old English word *giftan* meaning "to make a present of; to accord or yield to another; to grant by legal action; to administer as a sacrament, and to convey to another" (Mish, 2002). The term *care* comes from the old English word, *carian*, which refers to the concept of *troubling oneself*. The term is associated with three characteristics including attention to or concern for, responsibility for, and attachment to (Munhall, 1994).

Formal vs. Informal Caregiving

The term *formal* refers to what is done in accordance with rules of convention or constituting an official or important situation or occasion (Lexico, 2020). In Ontario's home care sector, formal caregivers are health care professionals who are authorized to offer payable caregiving services for people with medical needs. Both regulated (nurses) and unregulated (PSW's) health care professionals are considered formal caregivers. The Regulated Health Professions Act defines which professions are regulated, sets criteria for exemption, authorizes controlled acts and establishes requirements for each profession's regulatory college (Government of Ontario, 2020). Nurses are listed under the Act and have governing colleges which set out the standards and best practice guidelines for the profession (Hamilton, n.d). PSW's are unregulated care providers (Bryden, n.d). They are not listed in the Regulated Health Professions Act and do not have a regulatory college. While they do have an ethical obligation to promote good and avoid harm to patients, their conduct is not accountable to a governing body (Hamilton, n.d). Both regulated and unregulated health care workers can be employed by publicly funded home care agencies (contracted by the LHINs), by agencies which provide services for private pay and/or be self-employed. In all cases, formal caregivers in Ontario receive monetary compensation for their work.

The term *informal* is an adjective marked by the absence of formality/ceremony and refers to casual or familiar use (Mish, 2002). Drentea (2007) defines informal caregiving as the act of providing voluntary help and support to an individual (relative or friend) who has partially or completely lost the possibility of independent self-care due to physical, psychological, medical or developmental needs. The author differentiates caregiving from caring for children, which is referred to as *parenting*. If the parent provides assistance for a child that goes beyond the usual duties of parenthood, such services can be considered informal caregiving.

In different places across the world, informal caregiving in the home intersects with varying sectors of paid employment (public/private spheres) and unpaid work (domestic, voluntary) (Lyon & Glucksmann, 2008). As such, globally, there is no universal linkage between unpaid work and informal care or paid work and formal care. In other words, an IFC can be paid or unpaid and vice versa. The interaction of different forms of provision must therefore be analyzed in reference to the location of interest and its socioeconomic structure of care (Lyon & Glucksmann, 2008).

In Ontario, an IFC is an individual who provides care voluntarily or free of charge (unpaid) to relatives (the focus of this study), friends, and/or neighbors. The IFC is considered an unregulated care provider (Bryden, n.d). Informal care can be manifested in many forms which include personal/practical care and can be provided by any person who plays a role in the life of the elderly person or the person with disabilities.

Overview of Informal Caregiving in Canada and Ontario

The healthcare industry is facing substantial challenges from increased demand for home care services, resulting in higher reliance on informal care providers. Informal caregiving accounts for 80% of the care provided to the elderly and individuals with disabilities (Home Care Ontario, 2011). Statistics demonstrate that more than 8.1 million Canadians aged 15 and over provide informal care to a family member or friend (Statistics Canada, 2012). Those who are 45 to 54 years old provide the most informal care (24%), followed by those who are 55 to 64 (20%) and 15 to 24 (15%).

The majority of family caregiving is provided to parents or parents-in law (48%) (Statistics Canada, 2012). Caregiving for grandparents represents 13%, for spouses 8% and for children with disabilities 5%. It is not uncommon for caregivers to provide care to more than one individual. While 57% report providing care to one person within a period of one year, 27% and 15% report caring for two or three or more individuals, respectively.

Specifically, in Ontario, an estimated 3.3 million individuals or 29% of the province’s population are informal caregivers (The Change Foundation, 2016). “Eighty-four percent of caregivers are providing care to a family member; 47% of caregivers are looking after parents or in- laws; 24% are looking after a grandparent, sibling or extended family member; 7% are providing care to a spouse; and 6% are providing care to a child. Another 13% are caring for a friend, colleague or neighbour. Caregivers are caring for more female (57%) than male (43%) care recipients" (The Change Foundation, 2016, p.12)

Informal Caregivers report spending an average of 11 hours per week on care duties which include: emotional support and companionship; bathing, toileting, eating, and personal hygiene; transportation assistance; meal preparation, housecleaning and laundry; home and property maintenance; scheduling and coordinating appointments; medical treatments such as tube feedings, wound care and injections. Those who spend over 100 hours per week on care tasks most commonly look after individuals with Alzheimer's disease or dementia, mental illness, or cancer (The Change Foundation, 2016).

Although it is not always the case, most elderly and disabled persons prefer remaining in their home in their familiar surroundings, and informal caregiving can help them to maintain a high degree of self-governance and social ties. However, it should be noted that sending care home without providing the alternative of institutionalization, can sometimes mean an unwanted financial and time obligation on households (Aronson & Neysmith, 1997; Armstrong & Armstrong, 2004). Not all families have good social relations and not all care recipients want to feel that they are to be a burden on their carers. This can create tensions in the dynamics of the household. In addition, some families are characterized by violence and abuse, mostly directed at women, children and elderly. As such, the home environment in which care is to be provided should be considered. Nevertheless, the knowledge and extent of care provided by IFC may not be enough to meet the needs of the elderly or disabled person, thus, the professional services of formal caregivers are necessary.

Women as Informal Caregivers

Globally, women are the major providers of informal care for family members with disabilities and elderly with chronic medical conditions and/or aging needs (Sharma, Charrabarti & Grover, 2016). Research on this phenomenon has focused on the social, psychological and cultural demands placed on women to assume the role of informal caregivers. Numerous studies devoted to the examination of gender differences among informal caregivers of people with disabilities and the elderly, have demonstrated that women are more likely to devote more time to caregiving and are more diligent in carrying out personal care tasks than men (Brannen, 2006; Sharma, Charrabarti & Grover, 2016). Nevertheless, much evidence has demonstrated that female caregivers are mentally and physically strained and experience high levels of distress especially when there is little empathy and understanding of their roles (Sharma, Charrabarti & Grover, 2016; United Nations, 2009).

Highlights of a recent report on women's participation in caregiving, demonstrate that 30% of *all* women in Canada provided care in 2012 (Vanier Institute, 2017). Moreover, women aged 45 and older state that they spent about 5.8 years of their life providing care, compared with 3.4 years reported by men (Vanier Institute, 2017). In addition, Canadian women are more likely than men to report that they have spent 20 hours or more per week on care tasks (17% and 11%, respectively) (Vanier Institute, 2017).

In Ontario, women account for 53% (1.8 million) of informal caregivers, and men account for 47% (1.5 million) (The Change Foundation, 2016). Women spend more hours on care work with 29% female caregivers reporting spending 10 or more hours a week providing care when compared to 22% of male caregivers. In addition, women are also twice more likely than men to provide personal care tasks such as bathing and dressing (29% and 13%, respectively) (Statistics Canada, 2012). When it comes to paid labour, female informal caregivers are less likely than non-caregivers to be in the labour workforce. For men, being a caregiver does not impact their participation in the labour workforce (Lee & Tang, 2015). Finally, women who are employed, engage in more time caregiving regardless of their working hours, than their male partners (Brannen 2006).

Physical and Psychological Burden of Informal Caregiving

Informal Family Caregiving can provide women with a fulfilling experience; however, this activity may be associated with long-term challenges, affecting their physical and psychological well-being.

Physical Burden of Caregiving

Female informal caregivers often need to balance multiple roles including full-time paid work, household chores and caregiving responsibilities. Many informal caregivers become physically exhausted under such strenuous circumstances, in which they lack the resources and skills, as well as physical strengths to cope with accumulating demands (Pinquart & Sörensen, 2003).

According to Stenberg, Ruland and Miaskowski (2010), informal caregivers most commonly experience sleep disturbances, pain, loss of physical strength, poor appetite, and weight loss. In a study by Girgis et al. (2012) care work was found to have a direct influence on physical health, manifested in a constant sense of tiredness and exhaustion. Informal caregiving was also associated with back, neck, and shoulder pain, high blood pressure and heart problems, arthritis, and indigestion. When compared to men, women caregivers, especially those who are older, experience more sleep disturbances, poorer overall quality of sleep, and more impairment in daily function due to sleep loss (Byun, Lerdal, Gay, & Lee, 2016). In addition, women who experience increased stress from care tasks have significantly lower levels of the hormone estradiol and challenges coping with the many symptoms of menopause (Kroenke et al., 2004; Snelling, 2005).

Psychological Burden of Caregiving

Juggling multiple demands often takes a toll on the mental health of female informal caregivers. Those looking after individuals with disabilities or aging needs often describe a range of negative psychological effects, associated with poor recognition and lack of support for their roles (Statistics Canada, 2012; United Nations, 2009). This lack of support has been demonstrated to weaken mental health both for the informal caregivers and the care recipients (Romanow, 2002).

Informal caregivers report a constant sense of anxiety regarding their responsibilities and the need to spend much time with disabled individuals, who require physical and emotional assistance (Pinquart & Sörensen, 2003). As such, females providing care experience higher rates of depression, anxiety, and worsening of their chronic health conditions (Brannen, 2006; Gallicchio et al., 2002; Pinquart & Sörensen, 2003).

In Ontario, informal caregiver distress, anger and depression continue to rise. In 2017/2018, 26.1% experienced psychological challenges, when compared to 20.8% in 2012/2013 (Health Quality Ontario, 2018). According to the Change Foundation (2016) 55% of caregivers felt worried and anxious; 52% were tired; 38% were short tempered and irritable; 36% were overwhelmed; 18% felt depressed; 17% felt lonely and isolated.

Financial Burden of Caregiving

Women’s participation in the labour force has dramatically increased over the past half century, with those who are employed aged 25 to 54 rising from 37% in 1966 to 82% in 2016. Approximately 72% of female caregivers aged 45 to 65 have full-time jobs, making caregiving their part-time unpaid employment (Vanier Institute, 2017). Yet, often times employed women report an inability to manage their careers and caregiving responsibilities. They are obligated to either reduce the number of working hours, leave their employment, or retire early, affecting their financial stability and leaving them in a vulnerable economic situation (Lilly, 2011). Informal caregivers who provide care to their child have the most difficulty combining caregiving responsibilities with professional obligations and are more likely to take leave from work (Turcotte, 2015).

A report by the Vanier Institute (2017) demonstrates that Canadian women experience negative employment impacts as a result of their caregiving duties: 30% have missed one full day of work; 6.4% retired at an early age and 4.7% turned down a job offer or promotion. Women informal caregivers suffer from wage losses, as well as loss of employment insurance benefits. “Estimates have shown that the aggregated wages lost by caregivers due to absenteeism, reducing work hours or leaving employment entirely stood at $221 million annually for women vs. $116 million for men between 2003 and 2008” (Vanier Institute, 2017, p.2).

Almost 1 in 10 caregivers report financial hardship because of their caregiving responsibilities (The Change Foundation, 2016). Of these caregivers, 33% had to borrow money from a family member or friend; 34% had to take a loan from a financial institution; 20% had to sell assets; 77% had to use their savings to support their caregiving; and 90%

have had to modify their spending and budgeting.

In addition, IFC experience out-of-pocket expenses related to the care needs of their family member. For instance, those, who look after disabled children or elderly, report having additional expenses related to professional or rehabilitation services, not covered by provincial insurance (Turcotte, 2015). Furthermore, 52% of caregivers' report having to pay for medications for those spouses with disabilities. On the whole, these financial expenses can result in serious financial pressures.

A recent study by the CIBC aging parent poll examined the economics of caring for elderly parents. The report concluded in stating that aggregate direct and indirect costs of caring for elderly parents (out of pocket expenses and loss of labour income) is estimated to be $33 billion annually (Tal & Mendes, 2017). It also emphasized that the cost of caregiving has a greater impact on women and those with low-incomes. Accordingly, Canadians earning less than $50K per year spend an average of 30% more on care expenses relative to their salaries when compared to individuals earning over $100K. In addition, the research found that women take 30% more time off from work than men to care for aging parents, affecting their compensation. Taking into account the tendency of the growing population over 65, the financial burden on female IFC, especially those with low incomes who already find themselves in disadvantaged positions, is expected to rise (Tal & Mendes, 2017).

Men as Caregivers

In Canada, research has examined some differences between female and male informal caregivers. According to the Vanier Institute report (2017) discussed previously, 26% of all men in Canada provided care in 2012 when compared to 30% of women. Men spend fewer years of their lives on care tasks (3.4 vs. 5.8). When it comes to age, there is a higher gender gap of women providing care in their earlier years than men. This gap narrows as men and women approach middle age and is due to the fact that men more often provide care to their elderly spouses rather than to children or parents (Chang & White-Means, 1991; Lee & Tang, 2015). Furthermore, men less frequently engage in personal care work such as bathing and dressing (Brazil et al, 2009; Gerstel & Gallagher, 2001; Statistics Canada, 2012; Lee & Tang, 2015, The Change Foundation, 2016; Vanier, 2017).

According to Brannen (2006), men are less likely to suffer negative mental health effects. This has been attributed to the fact that informal caregiving is not central to their gender role, and thus, there is less pressure/fewer expectations associated with the performance of care tasks. In addition, men are more involved in instrumental caregiving such as repairs or handling finances as oppose to providing the more stressful and exhausting emotional support.

Lee & Tang (2015), found a negative relationship between IFC and participation in the paid labour force for women but not for men. Numerous research studies have indicated that women spend more hours on caregiving in the home regardless of their workloads when compared to employed men (Armstrong & Armstrong, 2010; Brannen 2006). Overall, it appears that men are less likely to be faced with the burden of a dual workday and thus, be less prone to physical/psychological burnout and financial challenges (Armstrong & Armstrong, 2010; Brannen, 2006; Doyal, 1995; Vanier Institute, 2017).

Caregiving: Gender Intersecting with Age, Race and Class

The above sections discussed the phenomenon of caregiving as being primarily the responsibility of women. Yet, since the study of health equity involves a specific focus on the populations which experience the most social obstacles, social categories of difference must be considered for a true understanding of varying circumstances and health outcomes. As such, this section explores the intersection of gender with age, race and class, for the purpose of providing a well-rounded overview of health inequalities as pertaining to caregiving (Hankivsky & Christoffersen, 2008).

Hofrichter (2003) speaks of the significance of the combination of gender and race when examining hierarchies of power. Oppressive practices stemming from the intersections of race and gender are clearly evident in the labour market. According to Browne & Misra (2003), education, experience, and skill do not entirely account for the substantial differences in labor market conditions. What is apparent, is the impact of race and gender on wages, and discrimination in the workplace. Due to their lower position on the socioeconomic hierarchy, women of colour are more likely to receive lower wages, be subjected to stereotypes and be discriminated in the waged labour market.

Most often, they occupy lower paying service and care jobs which lack security and benefits. This trend is particularly evident in Ontario's home care sector that is dominated by racialized PSWs. Statistics demonstrate that the overall visible minority population of Ontario is approximately 23% of the province's total population (Lum, Sladek & Ying, 2015). In comparison, visible minorities are over-represented among PSWs, making up 42% of the home and community labour force. This overrepresentation has been attributed to factors such as less Canadian work experience, lack of employment options and language barriers. In terms of wages, PSWs working in home care make $5-10 /hour less compared to those working in a nursing home or hospital (Kalenteridis, n.d). They also have irregular work hours and are offered fewer benefits.

Compounding gender and race is ageism. Older women of colour experience greater financial insecurity then their younger and non-racialized counterparts. These women experience compounded disadvantage due to their limited capacity to accumulate and sustain wealth over the course of their lives. During their working years women's incomes and work cycles vary. They often come in and out of the workforce due to caring roles, and have difficulty regaining employment after a work break. In addition, senior hood is highly gendered, as women live longer than men and are more likely to encounter financial struggles upon retirement. According to Hudon (2016), women aged 65 and over are more likely to live in low-income households than their male counterparts. Since women of colour have lower employment incomes compared to those who are not part of a visible minority ($39,330, compared with $42,848), they are even less likely to have accumulated savings for future retirement needs (ie. purchase of health services) and are more likely find themselves in financially compromised positions.

Finally, the argument for considering class stems from the realization that younger white middle-class women do not experience the same types of oppression as racialized, poor, and senior women. Gkiouleka et al. (2018) stresses the relationship between gendered oppression, class, and the silent voices of racialized women. The authors explain that poor and working-class people have less power to change/control their circumstance, and to gain a more equitable standing relative to their more privileged counterparts. Women of subordinate classes, races and ages often have little choice in the care and domestic responsibilities they assume. Furthermore, the devaluation ascribed to the paid and unpaid work efforts of women forces a disproportionate number of females to remain in subordinate positions in the social hierarchy. Consequently, many racialized, older and low-income women, find themselves in the most inequitable of circumstances, that impact health and ultimately survival.

In relation to home care, many female caregivers are older and looking after their family members. Those who are racialized may find it even more challenging than their non-racialized counterparts, to obtain respite from their caregiving duties (Doyal, 1995; Messing & Ostlin, 2006). This is due to financial strains which prevent them from seeking supplementary private services (above what is provided by the underfunded public home care sector). In turn, this may result in physical and psychological burnout. As already noted, to-date, the experiences of women as a whole with home care services (publicly funded and privately financed) have been poorly acknowledged, warranting the present study. More in-depth research of caregiving as pertaining to gender, race, age and class in the home care sector, is appropriate for future research. The next chapter turns to the discussion of the political, economic and historical contexts of home care in Ontario which allow the reader to understand the reasons behind the current challenges faced by IFC in relation to the sector.

Chapter Three
Political, Economic and Historical Context of Home Care in Ontario

Introduction

This chapter begins with a description of the macro political and economic context of home care in Ontario. The literature review of the historical happenings in the public and private spheres as stemming from the context will then be presented.

Political and Economic Context of Home Care in Ontario

The rise in neoliberalism has led many countries to develop policies aimed at restructuring the financing and delivery of health care through market-based models with the goals of reducing public spending and creating profitable areas for the business and corporate sector (England, Eakin, Gastaldo, & McKeever, 2007). The concept of “liberalism” dates to the mid-1770s, where social philosophers such as Adam Smith lobbied for a minimal role of the state in economic affairs. In the 1930s Liberal economics as a dominant political approach in many western nations was replaced with Keynesian economics which endorsed state intervention to even the ups and downs of the business cycle. At the same time a greater role for the State in managing the economy was seen as a means of promoting economic and social security for members of society, especially the most vulnerable (Briggs, 2006). However, the corporate and business sector’s drive for privatization within a free market economy unfettered by State control, gained momentum in the 1970s, creating a “new” liberalism or neoliberalism.

The theoretical assumption of neoliberalism and increasingly dominant narrative in the literature addressing health care reform proclaims that neoliberal or free enterprise strategies produce economic growth which in turn is the basis for all human welfare (Navarro, 2007). Yet, in actuality, in already liberal economies, driven by businesses and market forces, neoliberal ideology intensifies the differences in existing power relations increasing the ability of the corporate and business sector to influence public policy. These developments further skew the distribution of resources which promote health, thereby promoting social inequities which lead to health inequities (Coburn, 2010).

In Canada, the CHA has protected those services deemed medically necessary from competitive market forces as they remain fully funded and administered under conditions set by Medicare. Hospitals and physicians' services are treated as public goods and their purchase through the private consumer market is prohibited. On the other hand, the uninsured extended health services, beyond those protected by the CHA, have been subject to private market forces. Home care has become an opportunity for neoliberal-oriented politicians to pursue the implementation of market-oriented practices into the financing and delivery of services (England, Eakin, Gastaldo, & McKeever, 2007).

The neoliberal agenda for home care reform has included decentralization; i.e., the transfer of central government power to local/regional levels with the claim of reducing administrative redundancy, costs and meeting local needs. The justification for this is that inequities in access to care are a problem resulting from central government's lack of knowledge/ sensitivity to local populations. If care is distributed by smaller government bodies, the argument goes, the needs of residing populations can be better met (Armsrong & Armstrong; 2004; Aronson & Neysmith, 1997; McGregor, 200l). However, since smaller juristictions often have limited funding, the move to decentralize the home care system has resulted in funding shortages and diminished delivery of publicly subsidized care. Those individuals who find inadequacies with the public system, are thereby encouraged to turn to the private market for home care supports (McGregor, 2001). This illusion of choice of where to seek services and how much, is a primary goal of strategic neoliberal privatization reforms and can have a significant impact on the lives of patients and IFC, not necessarily for the better.

In light of the above, distinguishing between publicly funded and privately finances home care is of crucial importance. Publicly, services are provided at no cost to clients. On the other hand, privately, individuals must pay out-of-pocket for care, resulting in issues pertaining to equity. A thorough overview of the historical development of Ontario's home care system in relation to public/private will now be presented.

Evolution of Home Care in Ontario: Public and Private

Publicly Funded Home Care System in Ontario

Over the last six decades the home care system has undergone various changes to the structure and model of service delivery (Randall, 2007; Williams, 1996). Historically, the focus of governments in Ontario was on providing institutional care for the elderly. This system stemmed from the passing of the Elizabethan Poor Laws in sixteenth century England, when British workhouses were established to institutionalize those who could not take care of themselves (Association of Municipalities of Ontario, 2011). This system was then transported by British settlers to Ontario and LTC became associated with institutional care and loss of independence. Over the next 50 years services for seniors and those living with disabilities in the community were developed by municipalities and charitable organization. These were however, unregulated, unintegrated and varied in eligibility criteria. As the programs grew, overlap between different programs and levels of government involvement became apparent (Baranek, 2000; Williams, 1996).

Home Care Programs Before 1996

Prior to the 1950s Ontario's role in community services was limited to regulation. Government-funded home makers and nurses' services were first introduced in 1958 under *The Homemakers and Nurses Services Act (HMNSA)*. This program was not universal as homemaking and nursing services were provided only to some elderly, people with disabilities and those discharged from acute hospital stay, at the discretion of municipalities. The program operated on a 50:50 cost-sharing formula between municipalities and the province. The services were governed by the province (Ministry of Community and Social Services, MCSS), while being administered by municipalities which either provided services directly through Public Health Department municipal workers or purchased them from well-established non-profit agencies such as the Victorian Order of Nurses, St. Elizabeth Visiting Nurses Association, The Canadian Red Cross Society and the Visiting Homemakers' Association (Baranek, 2000, Ontario Secretariat for Social Development, 1981; Randall, 2007; Williams, 1996).

The primary goals of the program were to prevent hospital institutionalization or placement into LTC facilities. In the 1960s, amendments to the *Act,* including the allowance of services for preventative causes and the change in funding structure in which 80% of costs were shared by federal and provincial governments, resulted in increased accessibility to the program. Over the next 10 years the delivery of the services offered rose by 300% (Williams, 1996).

Launched shortly after the HMNSA were pilot projects including the Acute Home Care Program in 1958 and Chronic Home Care Program in 1975 (Randall, 2007; Williams, 1996). The Acute Home Care Program was developed by the Toronto Board of Health. The program's main purpose was to facilitate early hospital discharge through the allocation of temporary physician prescribed services. Services were initially directly charged to the client and adjusted based on ability to pay, but in 1972 become fully insured under the Ontario Health Insurance Plan (OHIP), administered by the Ontario Ministry of Health. By 1979 this program was expanded to the entire province to include northern and rural areas (Williams, 1996).

A Chronic Home Care Program was initially piloted in Kingston, Hamilton and Thunder Bay (Baranek, 2000, Randall, 2007). Requiring physician referral, OHIP fully funded a minimum of three home care visits from health care professionals per month. The purpose of the program was to provide continuing care in the home to individuals who would otherwise require institutionalization. As of 1981 the program was not universal across the province, being delivered to only 21 communities. Both the Acute and Chronic Home Care programs were based on a medicalized model where physicians were the referral source and gatekeepers to all health services.

A Need for Change

The perplexing split in jurisdictional responsibility between the MOH and MCSS, serving the same clients, with varying eligibility criteria and funding compounds resulted in a system filled with inequities that left individuals prone to institutionalization (Baranek, 2000). As such, the existing delivery model led to increased consumer concerns and criticisms over the unevenness of service provision and the difficulty in navigating and accessing care (Ontario Home Care Association, 2008). A need for change was evident as various advisory groups called for a comprehensive program that brought together services from MOH and MCSS under one funding structure with uniform eligibility criteria (Baranek, 2000).

In 1979, the province introduced the Placement Coordination Service (PCS) to assist individuals with the navigation of the complex LTC system. PCS was intended to provide a single point of access to information regarding placement into LTC facilities and community services (Randall, 2007; Williams, 1996). The program also arranged for assessments for community care including drop in-centers and home care. At the time, there were 36 Placement Coordination Service Programs operating in the province. Significant changes to the funding and delivery model were instituted in 1993 with the establishment of the MOHLTC and the introduction of the Multi-Service Agencies (MSAs) to replace the previous PCS (Ontario Home Care Association, 2008). The goal of the MSAs was to provide a single point of entry to the LTC system through integrated health, social and community services. The model was meant to amalgamate all provider agencies under one administration and decentralize coordination to district levels (Randall, 2007; Williams, 1996).

Under this amalgamation, all service provider agencies (existing and new) were to be employees of the administration and funding for services for individuals with long-term care needs would be provided through a fixed budget for each MSA. In addition, the MSAs were to provide caregivers with a network of support, a resource which was much needed. However, under the Ontario New Democratic Party (NDP), this reform was rejected on the grounds that the role of current smaller administrations was being threatened and feared that it would lead to decreased quality of service and volunteer participation (Ontario Home Care Association, 2008). At the time, both for-profit and not-for-profit provider organizations opposed the expropriation of their business activities by the MSA (Baranek, 2000).

Nevertheless, the seeds for amalgamation have already been planted and shortly after (in line with neoliberal ideology), the newly appointed provincial government, the Progressive Conservatives Party of Ontario introduced market mechanisms into the home care sector. On January 25, 1996, the MOHLTC announced a new structure as an alternative to MSAs, the emergence of Community Care Access Centers (CCACs) (Ontario Home Care Association, 2008). The model created a competitive process by which home care provider agencies would bid on a contract and "win" based on rigorous standards of quality including the employment of professional service providers at competitive wages, assurance of job continuity, and the deliverance of services at the best price to the public. The initial 43 CCACs across Ontario became the single point of access for coordinating the services which would then be contracted to private organizations for delivery of care. In 2007, the large number of CCACs were amalgamated into 14 CCACs, inheriting older contracts with providers.

With respect to the delivery of services, a system design that historically maintained the preference of a mix of not-for-profit and for-profit providers shifted to a structure that favored for-profit providers (See Table 1.) (Baranek, 2000; Ontario Home Care Association, 2008; Williams, 1996) As such, this major reform in Ontario's home care system has posed tremendous challenges to patients and their informal caregivers in reference to health equity as will be illustrated throughout this dissertation.

Table 1. Basic Summary of Historical Models in Relation to Home Care in Ontario

Model	Role	Financing for in-home services	Delivery of Services
Placement Coordination Service	- Information for services - Arrangements for assessments for community care	- For those over 65 - Direct provincial funding for in-home services (services purchased from external providers)	- Mix of not-for profit and for-profit providers
Multi-Service Agency	- Case management - Provision of in-home services	- For elderly and disabled individuals - Provincial funding for in-home services - Capped budget per MSA	- Single not-for profit agency per region - Employs service provider agencies directly
Community Care Access Centre	- Case management - Provision of in-home services	- For elderly and disabled individuals - Provincial funding for in- home services -Capped budget per CCAC	- Competitive Model - CCACs contract out service provider agencies to deliver in home care - Primarily for-profit service provider agencies

Market Competition- The Emergence of The CCACs

In Canada, the CHA protects those services deemed medically necessary from competitive market forces as they remain fully funded under Medicare. On the other hand, uninsured extended health services beyond those protected by the CHA, have been subject to private market forces. Home care has become an opportunity for neoliberal-oriented politicians to pursue the implementation of market-oriented practices into the financing and delivery of services (England, Eakin, Gastaldo, & McKeever, 2007).

Ontario’s managed competition model of community-based home care services was introduced in 1996 as a neoliberal-oriented reform with the claim of improving cost efficiency and control, and in theory promoting more equitable access to care (England, Eakin, Gastaldo, & McKeever, 2007). The model was considered a “mix” or “quasi-market” approach in the sense that private sector competition was publicly regulated to ensure that providers were accountable, and goals of access and quality were not subverted by the for-profit motive. The notion was that through managed competition, providers would bid for contracts from the CCACs based on offering services at the highest quality and best price. The lower costs achieved through competition would lead to expanded services for the aging population (England, Eakin, Gastaldo, & McKeever, 2007).

In general, market-based reforms assume fully functioning markets with the presence of adequate competition, a condition historically absent in Ontario’s home care sector due to the limited number of service provider agencies (Randall & Williams, 2006). Consequently, contrary to its stated objective, managed competition essentially led to decreased competition as a direct result of high barriers to entry such as the large costs associated with bidding for contracts by agencies (as much as $25,000 per bid). Smaller companies and non-profit agencies which were unable to absorb the expenses of applications had to close down offices and lay off workers, resulting in major disruptions in service delivery to clients and more pressure on informal caregivers (Randall & Williams, 2006).

Those agencies that were able to afford the bidding process, decided on the cost of their services leaving no choice for CCACs but to pay. A system which was traditionally managed by the non-profit sector was restructured to deliver services by a few large for-profit providers, similar to a market oligopoly. Thus, instead of reducing costs for services, the same service fees increased substantially (Randall & Williams, 2006).

In 2001, the MOHLTC froze public funding to home care on a per capita basis. This was done in order to ration public resources and enforce tighter controls on CCACs which ran out of funding near the end of every fiscal year but were always bailed by the ministry (England, Eakin, Gastaldo, & McKeever, 2007). Consequently, in order to remain within budget and offset the increases in service prices, CCACs had to reduce services to clients. Between 2001 and 2003, CCACs decreased the number of nursing hours by 22 percent, resulting in poorer quality of care. With budget deficits, and higher per-visit costs, the overall volume of services provided was further reduced, contributing to a decrease in the number of hours per client and a reduction in the number of staff (England, Eakin, Gastaldo, & McKeever, 2007). On the whole, the attempt at using managed competition to attract providers and to lower costs was unsuccessful in promoting equitable access to home care services. The reform used up the limited resources of agencies and CCACs, undermined continuity of care and created disruptions in delivery.

Competitive bidding was suspended in 2008 and finally scrapped in 2013. In theory, this move should have opened doors for smaller/non-profit agencies (thereby limiting privatization) to gain contracts with CCACs. Instead, the already existing contracts with larger for-profit provider agencies were frozen in place and have largely remained unchanged to-date. As previously implemented in the competitive bidding model, the current funding allocated to the sector is filtered through various levels of administration before reaching provider agencies (Ontario Health Coalition, 2015). Since private providers are skewed by profit motive, covering costs and generating revenue comes at the expense of diminishing services to clients. On the whole, limited funding available for direct patient care has not kept up with the number and complexity of clients requiring services. In

2015/2016 the CCAC received $2.5 billion in provincial funding, a mere 5.1 percent of Ontario's total health budget, a statistic close to that of 2000/2001 (Community Care Access Centre, 2015).

Local Health Integration Networks

In May and June of 2017, the 14 CCACs were merged into the 14 geographically aligned Local Health Integration Networks (LHINs) (MOHLTC, 2017). Although this system is currently in flux (as discussed below), the LHINs are Crown agencies established by the Government of Ontario to plan, coordinate, and integrate provincial health funding locally for hospitals, community health centers, LTC homes, mental health and addiction agencies and now also home care services.

The amalgamation of CCAC's into the LHIN stemmed from the *Patients First Act*, 2016 (MOHLTC, 2017). The act was part of Ontario Liberal Party government's Patients First: Action Plan for Health Care to create a more patient-centered health care system in Ontario. Under the Act, LHINs were to undertake both primary care planning as well as organization and management of home care services to ensure that patients are receiving coordinated and integrated care. The full implementation of the merger was expected to improve "local connections between primary care providers, inter-professional health care teams, hospitals, public health and home and community care to ensure a smoother patient experience and transitions" (Ontario Newsroom, 2016). In addition, it is rendered that integrating home care under the LHINs would reduce administrative and management costs so that savings can be reinvested into patient care. Each LHIN was to be governed by its own Board of Directors and meant to address the unique needs of communities by identifying local health care priorities. Although the evidence is still out, the LHINs were expected to improve access to care by ensuring more efficient allocation of resources as well as improve the overall patient experience and quality of care (MOHLTC, 2017).

This structural change in the health care system has been scrutinized by home care advocates. While upper management CCAC jobs have been eliminated as a result of the merger, the system continues to be impacted by private profit motive. The LHINs continue to contract private sector home care agencies to provide care, thereby maintaining a system where funds are being distributed to profit-taking middle people and away from patient care. In addition, as LHINs are already tasked with coordinating many services in the health care system, its amalgamation with the CCAC's may make it more difficult to manage caseloads in light of the rising demand for home care.

According to the Auditor General, LHINs lack the mandate and tools to align and integrate all health services (Glauser, Tierney, & Bournes 2016). Under their current mandate, they cannot hold some parts of their local systems accountable or manage improvement in many service areas. In addition, the LHINs have already been blamed for several shortcomings such as insufficient planning in the areas of palliative and community care. As such, the complex structural governance to take on a massive transformation to oversee hospitals, community care, primary care, and home care, leaves little opportunity for system wide integration (Glauser, Tierney, & Bournes 2016).

Recent Developments in the Home Care Sector

On February 26, 2019, Ontario's newly elected Progressive Conservative Party led by premier Doug Ford, unveiled a draft document entitled *The People's Health Care Act or Bill 74 (Ontario, 2019).* The bill proposes to create a Super Agency, called *Ontario Health* by dissolving the 14 LHINs and merging their duties with key agencies including Cancer

Care Ontario, eHealth Ontario, and Ontario Health Quality Council. In essence, this agency alongside the MOHLTC will oversee the province's $60 billion healthcare system and delegate funds to Ontario Health Teams which will be responsible for integrated care in their region (Crawley & Janus, 2019). Most recently, the Ontario government announced that it plans to invest an additional $124 million into the home care sector. How this amount is calculated and whether it is based on actual need is unclear (Ontario Newsroom, 2019).

The Ontario Health Coalition, which advocates for public healthcare, has scrutinized the bill stating that "what is actually written in the legislation is that the Minister and the Ford Government have given themselves vast powers to order health service closures, transfers, mega-mergers, and the like, including powers to privatize and to facilitate the for-profit privatization of significant parts of our public and non-profit healthcare services" (Ontario Health Coalition, 2019). Particularly for the home care sector a move towards the privatization of health-care, is not drastic as it is already a publicly-funded, privately delivered partnership model. However, the expiry of the LHINs can potentially mean that for-profit providers will have less accountability and supervision and thus, the freedom to drive up costs for their services, use up funding for for-profit motive while reducing patient care. To-date, it remains unclear how contracts for home care will be managed, and how the coordination of home care delivery will be accomplished.

Demand for Home Care

Over the last decade the demand for home care services has risen substantially due to a number of factors including: the growing population in Canada, the growing number of individuals over the age of 65, the increasing rates of complex and chronic conditions, trends to faster hospital discharge, and advances in treatments/technologies (Landry et al., 2008). According to Statistics Canada, the population of Canada increased by 5.0% between 2011 and 2016. Specifically, in Ontario, the population increased by 4.6% during this period (Statistics Canada, 2016). This increase in population has been identified as the driving factor behind demand for home care services (Landry et al., 2008).

On closer examination, of particular relevance to aggregate demand has been the increase in the number of individuals over the age of 65. It is estimated that older citizens are expected to double in number from 5 million in 2011 to 10.4 million in 2036 (Canadian Home Care Association, 2014). By the year 2041, approximately 25% of the Canadian population will be over the age of 65 (Landry et al., 2008). In addition, medical advances are enabling individuals to live longer with a multitude of chronic conditions including: HIV, diabetes, heart disease, and cancer. Conditions which once were fatal in infancy are now being treated resulting in longer life expectancy as well as the likelihood of living with a disability. In Ontario, approximately 80% of individuals over the age of 45 are living with a chronic disease. Finally, the trends in hospital discharge have led to more individuals being sent home faster with acute and complex conditions requiring integrated home care services (Landry et al., 2008).

The number of people served in Ontario has more than doubled since 2003/2004 (Central East Local Health Integration Network, 2016). In 2015/2016 CCACs served more than 729,000 individuals in their homes, delivering over 37.7 million visits from nurses, rehabilitation professionals, social workers and dieticians (Home Care Ontario, 2017). Since 2008/2009 the demand for home care has been steadily rising, with a 19% increase in new CCAC admissions (Community Care Access Centre, 2015). In addition, there has been a 95.3% increase in the complexity of patients between 2010/2011 and 2016 requiring coordinated home care from multiple professionals. With the evident increase in demand and patient complexity, funding has already emerged as a critical policy issue.

Privately Financed Home Care System in Ontario

A private home care agency may or may not have a contract with the LHIN. Those agencies which have contracts provide services which are both publicly funded and privately paid for. Purchasing services from private home care agencies serves its purpose by giving individuals an opportunity to live at home with independence as well as offering solution to their health-related challenges, outside of the bounds of the publicly funded system. In addition, private services allow for greater respite for IFC from caregiving duties as well as the opportunity to fulfill other responsibilities such as raising children and/or holding a job. Some of the reasons why individuals might choose to pay directly for private home care include: not meeting the eligibility criteria for publicly funded care, needing additional care than what is allocated, or simply wishing to forgo the public system alltogether. Families that can afford to pay for in-home care are able to decide on the agency, the number of hours and services they require. In Ontario, one in five individuals is an IFC and an estimated 150,000 persons purchase home care services privately. Annually, over 20 million visits/hours of direct home care services are purchased and often to supplement the publicly funded system. This equates to approximately 2.56h of purchased care per person, per week (Home Care Ontario, 2014).

Private home care agencies both for profit and not for-profit have long been established in Ontario. For example, one of the most well-known non-profit agencies, VON, was established in 1897, by Lady Ishbel Aberdeen, wife of Canada’s Governor General, in response to the critical shortage of nurses in rural and under-served areas (VON, 2018). Services provided by VON spread quickly across the country and have helped communities through many devastating periods in history including World War I, the Great Depression and World War II. At present, VON staffs over 5,000 health care professionals across the country, providing in-home services through the General Home Visiting Nurses Program. VON has contracts with the LHINs in some areas but services can also be purchased directly.

To date, there is little information about the extent to which individuals and their families purchase home care services privately. This is due to the fact that private home care agencies are neither regulated nor required to disclose any information to the public. In addition, there has never been an official registry where all operating private home care agencies were obligated to advertise their services. However, it is understandable that the private-sector component of home care in Ontario has risen as a result of the combination of the shift of care into the home and community, and the emphasis within the health sector on cost containment in publicly funded care. Individuals that were left stranded with unmet care needs due to a lack of public services, now had to search for other sources of support.

In 2007, Guerriere et al. conducted a study using quantitative analysis to examine the costs and predictors of usage of privately financed home care services in Ontario. Data was collected from 514 participants from six regions. On average, individuals spent $130.37 per week on private expenditures which included consultations with healthcare professionals, household help, medications and travel expenses (Guerriere et al., 2008). The authors demonstrated that markers such as age, impairment, being female, and having multiple chronic conditions, predicated higher private expenditures. They also noted that higher public expenditures were associated with higher private expenditures due to the increasing care needs of the individual. The researchers concluded by stating that a greater appreciation for privately financed care is warranted in order to better understand the needs of clients and caregivers, and inequities in access to the system (Guerriere et al., 2008).

Home Care Ontario, formally known as The Ontario Home Health Care Providers' Association (OHHCPA), is a membership association which represents providers of quality home care services from across Ontario (Baranek, 2000; Home Care Ontario, 2014). Established in 1987, the association had initially represented only for-profit home care agencies. However, in 2002, a number of agencies with publicly funded contracts from the CCAC requested and were granted membership rights. Home Care Ontario is considered *the voice on home care in Ontario* (Home Care Ontario, 2014). Its primary goals are to provide support to members, to represent members' interests to government, and to build the home-care industry. Over the years, the organization has promoted the growth and development of home care advocacy, knowledge transfer, and leadership by producing research, recommendations, and services to best serve its member agencies, and ultimately patients. The organization acts on behalf of members on topics such as government policy changes, consumer trends, and employment practices.

On the public side, Home Care Ontario advocates for funding, delivery and equity in the home care system. Publicly financed agencies must achieve accreditation by approved organizations such as Accreditation Canada, FOCUS Accreditation, Canadian Centre for Accreditation, and CARF Canada, and/or be registered with the International Standards Association (ISO) (Home Care Ontario, 2014). On the private side, the organization supports quality services offered to individuals by both non-profit and for-profit organization in their endeavors to deliver privately financed care in response to the growing demand in the system. On the whole, all members of Home Care Ontario should maintain best practices when it comes to professional College standards and guidelines, financial and commercial standards and health protection and infection control procedures.

Standardization and Best Practice Guidelines

Numerous times in this document the popular terms *standardization* and *best practice* are presented and thus, they require a closer examination. Standardization refers to the process of rendering things uniform and standard to the means and outcome of standardization. Standards are implemented based on consensus and are meant to promote safety, repeatability and quality (Timmermans & Berg, 2010).

Of particular relevance to standardization is the emphasis on the practice of Evidence-Based Medicine (EBM), or “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al., 1996, p.71). EBM is the foundation for best practice guidelines which integrate research and practice for clinical decision making (Driever, 2002). Best practice guidelines need to be: patient centered, scientifically based, population outcomes based, refined through quality improvement and benchmarking, individualized to each patient, and compatible with system policies and resources (Driever, 2002).

While standardization and best practice guidelines are widely recognized in medicine, their use is debated (Timmermans & Berg, 2010). Proponents argue that evidence based guidelines can provide transparency about clinical decision making. Allowing for a better understanding of the process can facilitate its regulation as well as open up a new means to achieve cost efficiency. In addition, health care professionals see guidelines as a crucial aspect of professional status as they provide a knowledge foundation of scientifically based interventions/procedures for use in practice. On the whole, supporters of standardization advocate for the practice of EBM stating that it leads to improved quality of care, better health outcomes, more educated patients and clinicians, better coordination of research activities, cost efficiency, and scientific guidance for public policy (Timmermans & Berg, 2010).

On the other hand, critics argue that evidence is rarely available to guide all aspects of clinic decision making (Timmermans & Berg, 2010). They note that methodological problems in clinical trial research may result in inefficient standards and misinformed guidelines. In addition, following uniform procedures which have been defined by others as best practice, undermines clinical experience and intuition, resulting in the loss of professional judgement regarding individualized treatment. Finally, different professional groups may formulate opposing guidelines or nomenclatures, the competition of which, may sabotage the uniformity required for standardization.

In the present study, home care service providers should maintain best practices as per their professional College standards. Yet, while constituents for EBM are decided by experts, becoming acquainted and following best practice guidelines remains up to the health care professional. As clinicians vary in their knowledge, and expertise, the application of best practices to care work may not be consistent. In addition, since the decisions regarding the delivery of care are limited by funding and the promotion of cost efficiency, standardizing the delegation of care based on need may be challenging. This phenomenon will be explored through the voices of IFC.

Considerations for Private Care

In the publicly funded system, individuals usually have little to no say in which agency or providers deliver their services, while in the private sector, this choice can be made. However, as there is no regulatory body to oversee the quality of services delivered, clients must carefully analyze the agency/independent service provider they contract. According to Home Care Ontario (2014), families are unaware or uncertain of the risk inherent in directly hiring care. In brief, it is important to mention the points for hiring a reputable agency or independent service provider because this illustrates the differential in the choice in access that the publicly funded system does not offer.

1. Membership/registry: Home care agencies that are members of an association, such as Home Care Ontario, generally value practice standards. Agencies which provide both publicly funded (have current contracts with the LHINs) and privately financed services are generally accredited, which indicates commitment and reputability.

2. Price: Agencies which cost more may be more reputable and pay their staff higher wages resulting in greater job satisfaction, and better quality of service (Closing The Gap Healthcare, 2018). On average, the cost of a PSW is between $20-$30 per hour and RPN/RN between $50-$60 per visit (Comfort Life, n.d).

3. Years in Service and Rating/Reviews: Hiring providers from an agency that has serviced the community for many years and has positive feedback, is generally preferable due to their established reputation within the community.

4. Service Providers

In order to avoid potential safety hazards as well as fraud, it is crucial to make sure that service providers delivering care have the credentials to provide the service. For instance, to become an RN, one must obtain a bachelor's degree from an Ontario University. Nurses are regulated health care professionals who have a governing college and should conform to best practice guidelines. Should an issue of care arise, recipients may make a complaint to the governing college regarding the practitioner. This ensures the safety of clients.

In order to become a PSW in Ontario, one must pursue education and obtain a diploma from an institution that is accredited by the Ministry of Training, Colleges, and Universities. Although PSW's are not regulated, they should abide by ethical standards while providing excellence in care.

5. Customer service, provider hours, consistency and language

An agency that has reachable and attentive customer service and is available 24/7 demonstrates a good sign of customer commitment. Agencies which can accommodate the hours requested by clients, do not have frequent cancellations and are able to offer the same care provider, result in less stress for families, as well as respite for the informal caregiver.

Having reviewed the background and considerations for both the publicly funded and privately financed home care services in Ontario, the next chapter turns to the discussions of the theoretical frameworks utilized in the analysis of the home care system in Ontario and the present research.

Chapter Four
Theoretical Frameworks

Introduction

This chapter begins with the FPE framework which documents the impact of socio-economic policies on states, markets, and households as pertaining to paid and unpaid labour. Prominent works by Armstrong (1997), Armstrong & Armstrong (2004), Armstrong & Armstrong (2010), Aronson & Neysmith (1997) and Luxton & Bezanson (2006), provide a broad spectrum of feminist considerations for understanding the experiences of women in the public realm of production and the private realm of the household related to the provision of care. Next, the discussion turns specifically to FPE and unpaid caregiving in Ontario's home care system.

Finally, this chapter will address the SDOH framework to discuss how the distribution of income, and access to health care (home care) services, impact the health outcomes of female IFC (Raphael, 2016). These categories are most relevant to the present research.

Feminist Political Economy

Political Economy, for the most part, disregards matters of gender in a market economy which is sustained and depends on the provision of unpaid labour in the home. As such, the work of FPE builds on the more dominant perspective of PE and identifies the uncompensated work of nurturance and care as an economic category with production and consumption of both paid and unpaid work, generating the household's livelihood (Armstrong & Armstrong, 2010; Riley, 2008). FPE applies a gendered lens to the labour market, as experienced by women. In doing so, the FPE framework seeks to explain inequities in health as stemming from the division of labour in society which assigns both paid employment and household work, including that of care, to women (Armstrong & Armstrong, 2004; Armstrong & Armstrong, 2010; Armstrong & Connelly, 1989).

From the standpoint of FPE, the terms public and private have dual meanings (Armstrong, 1997; Armstrong & Armstrong, 2004; Armstrong & Armstrong, 2010). One way to conceptualize public vs. private, is to consider the divisions within the formal economy. Services and supports established by the government can be viewed as public, while services or goods that are provided by organizations (for profit or non-profit) are of private nature. The second way to conceptualize public vs. private is to consider the formal economy (the labour market) as public and the sphere of the household as private work. The distinction between the two meanings as well as their intersection, is very much governed by state initiatives. For example, the state can provide public supports for the private household (i.e., home care services), which would otherwise be, for the most part, the responsibility of unpaid women. The state can also intervene by setting the conditions for employment in both the public realm of the labour market and the private realm of the household. As such, the state is central in constituting what is public and what is private (Armstrong, 1997; Armstrong & Armstrong, 2004; Armstrong & Armstrong, 2010; Aronson & Neysmith, 1997). By understanding the historical context of state interventions and the relationship to markets and households, we can better appreciate the forces that have set the conditions for women's paid and unpaid labour. It is through this analysis that we can shed light on the circumstances necessary for delivering good care and creating policies aimed at diminishing health inequities for those who provide it.

The following section, will explore the historical context of state interventions, their relationship to market economies and resulting experiences of women in the public realm of production and the private realm of household as pertaining to the provision of care (Armstrong & Armstrong, 2004; Aronson & Neysmith, 1997). In addition, the concept of social reproduction will be presented as embedded within the framework of FPE (Luxton & Bezanson, 2006). Social reproduction refers to anything having to do with the maintenance and reproduction of people, particularly the laboring population in the provision of basic necessities required for survival. Social reproduction furthers the debate regarding public and private spheres and allows for a deeper understanding of how the interaction between the state, market and household, impacts the production and maintenance of individuals (Luxton & Bezanson, 2006).

States, Markets, Households and Labour (Paid and Unpaid)

Until World War Two (WWII), the majority of women worked primarily within the home, either for their own family or for an employer's (Armstrong, 1997; Armstrong & Armstrong, 2010). Domestic production of various goods was a means of survival which also meant that women's work was visible and they were appreciated as economic partners. By the nineteenth century, industrial capitalism was assuming a new prominence. Manufacturing and trade were on the rise and the production of goods which had previous earning potential from the home, was replaced by factories, offices and stores (Armstrong & Armstrong, 2010). As such, women began to rely on men for access to market goods and the segregation of home and work progressively emerged. At the same time, the incomes of males failed to keep up with household economic requirements and women needed to seek employment in the formal economy. While men found jobs in more male dominated professions (mining, construction), women's contribution to the labour market was in the public or service sector, where they engaged in similar tasks to domestic labour. This segregation into female dominated jobs, which were of lower pay and more often on a part-time basis then male dominated jobs, positioned them to be of lesser value (Armstrong, 1997; Armstrong & Armstrong, 2010).

The period after WWII, until the mid-1970s became known as the golden years which marked a prominent emergence of welfare state interventions (Armstrong & Armstrong, 2004). At the time, governments at all levels were faced with pressures from unions, veteran's and women's organizations to provide supports for families so that they could meet the needs of post-war challenges-prolonged unemployment, and caring for those with disabilities, and illnesses. In response to these pressures, the state expanded its social programs to bear the responsibility for the welfare of its citizens. However, not all programs benefited all individuals (unemployment insurance and worker's compensation, were mostly applicable to men), and those that did were critiqued to perpetuate women's dependency. Nevertheless, improved health care and labour supports (minimum wage laws, overtime regulations) in particular, meant that the overall quality of living for women improved (Armstrong, 1997; Armstrong & Armstrong, 2004). In addition, state interventions in the formal economy created many good jobs in the public sector related to health and education. Since women needed income and had the *skills* for these jobs, the paid work of care came into view. Furthermore, women's increased economic contribution to the household, gave them the advantage of decision making powers for the family as well as their personal lives (Armstrong, 1997; Armstrong & Armstrong, 2004).

The period of the golden years marked an important distinction between public and private in both senses of the words (Armstrong & Armstrong, 2004). In the market, women occupied jobs in both the public sector (health care, education), which required the skills related to care work similar to those of home, and the for-profit sector (ie, retail- which expanded with capitalism), for which the skills did not resemble domestic work. Since many women worked for pay outside the home, it became easier to distinguish the formal economy from the household. In the home, however, the welfare state did not fully provide public programs to take over the work of care. As such, the segregations of women's unpaid care work in the household and that in the formal economy, was not entirely distinct, visible or appreciated (Armstrong & Armstrong, 2004).

One significant event that took place in 1953 (subsequently revised) and contributed to the devaluation of women's unpaid care work was the publication of the System of National Accounts (SNA) under the United Nations Statistical Commission (UNSC) (United Nations, 2020). The purpose of the SNA was to provide an accounting framework to include a complete system of accounts and enable international comparisons of all significant economic activity. Having a system of comparability would allow for analysis and evaluation of an economy and direct policy making in the needed areas (United Nations, 2020). With regards to the unpaid work of household and care, the UN deemed it to be of little to no importance, thereby excluding it from the SNA (United Nations, 1953; United Nations, 2009). This omission was strategic because it was known that household and care work were primarily done by women (for whom it was considered *natural*) and that it was the biggest sector in the nations' economies. Yet, since quantifying and putting a market value on this type of work was challenging, it was conveniently deemed unfit for economic analysis. Had this been done, a significant portion of health care budgets would have had to go towards the carers (primarily women). By excluding household and care work from the SNA and making it invisible, policy making and the implementation of programs that would better the conditions for unpaid carers continues to be deliberately slowed (United Nations, 2009).

Moving forward, the shift towards market mechanisms (neoliberalism) and the progressive retreat of the state, from the mid 1970s, marked a prominent transformation in the social rights of individuals and particularly, women's work in the public sector and private household (Armstrong, 1997; Armstrong & Armstrong, 2004; Armstrong & Armstrong, 2010; Aronson & Neysmith, 1997). In the formal economy, the state pursued market oriented practices such as cuts to public service and privatization. This meant that many of the good jobs women had in the public sector began to disappear. The gains that women had made earlier declined dramatically with Ontario's 1995 election of the Progressive Conservation Party led by Mike Harris (Aronson & Neysmith, 1997; Luxton & Bezanson, 2006). From the mid 1990s and onwards, is where neoliberal order and ideologies really took rein (in home care, market competition/CCAC's were introduced, see chapter 3). Decision making was placed in the hands of those who had power and social and household issues, became the responsibility of individuals.

As welfare state initiatives decreased and labour market policies prevailed, public supports including those of healthcare, education and community services eroded, resulting in constraints to the conditions required for social reproduction (Luxton & Bezanson, 2006). In both the household and marketplace, the work of social reproduction became unequally redistributing and for the most part, taken up by women. Socially reproductive activities which formally took place in public spheres such as daycares, hospitals, communities and elderly homes, were transferred into the private sphere of the home, where women absorbed their labour and associated costs (LeBaron, 2010; Luxton & Bezanson, 2006). Those households that could afford it, hired individuals from the private marketplace to carry out the activities for social reproduction, while women from lower income households either took on greater workloads or had to diminish their standards of living (buy cheaper food, move into cheaper housing and/or go into debt) (LeBaron, 2010). In the private marketplace, social reproduction became evidently more gendered, racialized and minimally valued as many of the good jobs in the public sector were removed. It is women, and more often women of colour that take on these jobs of care, which in the private marketplace are typically precarious and of lower pay (Luxton & Bezanson, 2006).

In sum, the traditional structure of the family has changed from one in which the man was the breadwinner and the woman was primarily a homemaker (who also did incoming generating work if needed and possible) to that of the woman participating in the waged labour market[2]. The outcome has been such that while men continue to make their primary contribution in the public sphere of the waged labour market, women now tend to occupy both the public and private domains (Armstrong & Armstrong, 2004; Armstrong & Armstrong, 2010; Doyal, 1995). Societies which diminish welfare state initiatives and adopt the neoliberal philosophy supporting self-serving individualism and market participation through paid labour, disregard values such as compassion, duty, and reciprocity. As such, the care of family or traditional work of women is conveniently undervalued, unpaid for or even looked down upon (Armstrong & Armstrong, 2010; Aronson & Neysmith, 1997). When it comes to the paid labour market, it is both highly gendered as well as racialized. Women have significantly less autonomy and fewer opportunities than men to advance, and

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[2] Note that racialized women and working class women have historically engaged in both paid and unpaid labour.

the majority of their work in the public sphere is similar to the unpaid duties they perform in the private realm of the household. Women, especially those who are racialized, have less education or have significant caregiving responsibilities, are more likely to occupy lower paying jobs such as cleaning, and care work, as well as contract or part time work. These jobs are typically non-unionized, lack security, career advancement, and employment benefits (Messing & Ostlin, 2006). Work scheduling usually does not consider the availability and needs of women who have children and elderly in their care. Without adequate social supports, it becomes very challenging for households to manage social reproduction on their own, resulting in diminished standards of living. For women, in particular, managing the multiple roles of a dual work day, often leads to economic vulnerability and inequitable health outcomes.

The next section turns specifically to the discussion of FPE and the formal (paid) and informal work of caregiving in Ontario’s home care sector.

Feminist Political Economy- Caregiving and Ontario’s Home Care System

In a work force dominated by women, the introduction of neoliberal market-based health care reforms greatly impacts the experiences of female formal and informal care providers by affecting their work, financial stability and ultimately health (England, Eakin, Gastaldo, & McKeever, 2007). This trend has been particularly evident in the home care sector since the introduction of managed competition (England, Eakin, Gastaldo, & McKeever, 2007).

With this reform, the duration of visits was cut short due to administrative (documenting, charting) obligations and respect for professional judgment with regards to the number of treatments recommended was eroded. In addition, in an attempt to become more competitive, agencies demanded more from providers, increasing their workloads in an already labour-intensive job. Meanwhile, only self-employed professionals were hired, primarily women, with no guarantee of work hours and little to no benefits. In the broader context of female dominated professions where there are fewer employment benefits and lower pay, the wage gap in care work became especially evident in the home care sector, as agencies further lowered payments to remain competitive. Subsequently, women left for employment in other health care settings, leaving agencies understaffed, the remaining employees overworked and clients underserved (England, Eakin, Gastaldo, & McKeever, 2007).

Budget deficits and the limited availability of home care services have placed the burden of care on informal supports, primarily female family members. According to Health Quality Ontario, the amount of informal care provided rose from an average of 18.8 hours per week in 2009/10 to 21.9 hours per week in 2013/14 (Health Quality Ontario, 2015). The majority of patients are cared for by a child or child in law, while others are cared for by a spouse. Fifty six percent of individuals who look after family members with poor cognitive functioning, high dependence with activities of daily living, presence of behavioural issues and high frequency of falls, report caregiver distress (Health Quality Ontario, 2015). Women most often take on the role of caregiving for their spouse (76.3% vs. 36.6%). Male spouses often present with greater physical and cognitive impairments than their wives (Gruneir et al., 2013). In addition, female spouses are usually older and dealing with their own poor health or daughters have to juggle paid work and home demands. Consistent with neoliberal ideology, care is considered the “natural” work of women both at home and in the workplace. As such, there are no programs which provide IFC with financial compensation for their time and energy. The next section turns to a discussion on the SDOH which include gender, income and health services and their relationship to caregiving and health equity.

Health Equity and the Social Determinants of Health

SDOH are the societal conditions which encompass individual's lives. According to Raphael (2016) there are 14 SDOH which are related to one another, and act as co-determinants of health. Considering the SDOH enables a broader insight into health inequities, as resulting from varied access, and distribution of resources. As such, this model rejects lifestyle and/or biological frames that attribute health to one's own personal choices or biology (Raphael, 2016). According to the Committee on Economic, Social and Cultural Rights (CESCR), patterns of discrimination and exclusion from the access to the SDOH significantly influence health and health equity (Chapman, 2010). In other words, inequities in access to the SDOH hinder individuals from attaining a standard of living exhibited by the privileged in society and ultimately lead to poor health and diminished quality of life.

Below is a general discussion of the SDOH that emerged as most relevant to the present research- income, gender and health services. The dialogue then turns specifically to these SDOH in relation to the IFC of Ontario's home care system.

Income

Research has shown that income, the distribution of which is skewed in liberal welfare states, is one of the most prominent SDOH (Raphael, 2016). It defines one's socioeconomic status and impacts other SDOH such housing, education and access to health services (i.e. privately financed home care). In Canada, the level of income one is able to maintain shapes their overall living conditions, physiological and psychological functioning and influences health related behaviours. Overall, the cumulative effects of stress resulting from inequities in income distribution have shown to weaken resistance to disease and alter individual bodily function, especially in terms of hormonal and metabolic systemic function, eventually leading to chronic diseases, poor quality of life and premature death (Mikkonen & Raphael, 2010).

Gender

Women experience multiple disadvantages in relation to the access to social and economic resources (Doyal, 1995; Gkiouleka, 2018). As discussed earlier in this text, neoliberalism fosters an oppressive market environment for the vulnerable, many of whom are women. When compared to men, women tend to occupy lower paying jobs with no security or benefits (Messing & Ostlin, 2006). When it comes to income, research indicates that women earn a fraction of what men earn through paid labour, resulting in higher cases of poverty (Bryant, 2009). Poverty then directly impacts the access to a number of SDOH including food, shelter, and health care which in turn, increases the likelihood of inequitable health outcomes (Raphael, 2002).

Health Services

Access to high quality health services is both a SDOH and a basic human right (Raphael, 2016). In Canada, the CHA reinforces the conditions and criteria to which individual provinces and territories must conform, in order to receive funding for health care services (Madore, 2000). The act defines five national principles to which jurisdictions must abide. However, these principles apply only to those services deemed medically necessary, in hospitals and by physicians. Services which are not considered medically necessary must be paid for either out-of-pocket or through private insurance. As such, even though the CHA states that every Canadian should have uniform access to health care services and not be discriminated based on gender, race, income etc., in actually, inequities in access to care are overwhelmingly evident. Canada ranks among the lowest in its public coverage of total health care costs (22 out of 30 OECD nations). Medicare only covers 70% of health care costs while the rest is covered by private insurance plans and out-of-pocket expenses (OECD, 2011).

Home care specifically, is considered as extended health care under the CHA and thus, there is no assurance of coverage for the delivery of services across the country (Madore, 2000). In Ontario, funding for home care is a mere 5.1 percent of a province's total health budget. As such, the provision and access to services for those who need them is not guaranteed. In relation to gender, female IFC juggling multiple tasks are often unable to participate fully in the paid labour market, resulting in financial difficulties. With limited monetary resources, it is challenging to pay for and access private home care. In turn, increasing the burden of care for the IFC and the likelihood of physical and psychological burnout. On the whole, neoliberal state policies which limit public spending on health and social programs lead to individuals having to spend more of their incomes on the SDOH (housing, education, health services) (Bryant, 2009). This is particularly the situation for low-income individuals as a result of their already disadvantaged position in the socioeconomic hierarchy (Armstrong & Armstrong, 2010).

SDOH: A Look at Access to Home Care Services in Ontario

Equitable access in health care refers to the opportunity to obtain services on the basis of perceived need. In 2013, the Ontario government set a goal of introducing a five-day target time for the initiation of in-home nursing services. On average, 93.6% of authorized clientele received services within the first five days (Health Quality Ontario, 2015). While this figure looks promising, since there is no guarantee of service provision, the number of visits and quality of care likely remains inconsistent across regions. In 2015, CCACs[3] received different amounts of funding and funding rates varied for agencies across the province (Grant & Church, 2015). Patients appeared to be entered into a postal code lottery, their care based on their geographic location. In addition, there was no uniformity among CCACs on the criteria to determine eligibility for care. There was inconsistent scoring on the Resident Assessment Instrument-Home care, one tool used to evaluate the number of hours of care a patient should receive. CCACs required different scores on the instrument to qualify the applicant for personal support, representing a dramatic difference in the patient's condition and need for the services (Grant & Church, 2015).

Furthermore, some CCACs funded post-surgical equipment such as walkers while others did not, another determinant of geographic location and allocated funding. In some cases, funding became so stringent that IFC were pressured into performing medical duties such as dressing wounds, and changing intravenous bags (Grant & Church, 2015). Eligibility varied between CCACs, and changed monthly depending on arbitrary budget levels. To date, the number of people trying to access care and failing is not being measured and thus, there is no way to know if target funding is ever sufficient (Ontario Health Coalition, 2015).

Inequitable access to care for those who require it, leads to increased hospitalization rates, institutionalization, and premature death. In addition, limited funding and access to services greatly impacts IFC distress (primarily women). As such, the experiences of IFC

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[3] There is no research on this data for the LHINs

with the publicly funded home care system must be considered. In line with the goals of market-based reforms, public health care systems become so undependable/unreliable and inefficient that individuals must turn to buying private health care (home care) services in the marketplace if they can (as discussed in chapter 3) (McGregor, 2001). Thus, visible inequities in access stemming from varied financial positions and income inequalities directly impact the care obtained. Those who cannot afford to pay for private home care are marginalized into receiving insufficient services, resulting in differential health outcomes.

On the whole, by illuminating micro level individual informal caregiver experiences in relation to their political and economic context, policies, care, and service provision can more adequately address issues concerning equity and health. Hence, the present work applying both the FPE and SDOH frameworks, is important for the sake of effective health services, policies and research mechanisms.

Chapter Five
Methods

Research Approaches

This research employed a mixed-methods approach to capture the lived experiences of IFC with both publicly funded and privately financed home care services. This chapter begins with the presentation of phenomenology the chosen qualitative method and its application to the present research. Next, the dialogue turns to an overview of the chosen quantitative research methods, the surveys and their applicability. Finally, the benefits and limitations of using a mixed methods approach are reviewed. The remainder of the chapter addresses research design and analysis.

Phenomenology as a Qualitative Research Method

Phenomenology is derived from the Greek words phainomenon (appearance) and logos (reason or word) (Stewart, 1974, P.3). Thus, *Phenomenology*, is in other words a *reasoned inquiry* into the nature of appearances, whereby appearances refer to anything of which one is conscious (Madjar, 2016). In research, the main objective of phenomenology is to investigate, describe and understand individuals' perceptions, perspectives and interpretations of a particular situation or phenomenon as they personally experience it (Schumacher, 2010). By examining multiple individuals' perspectives of the same situation, a researcher can then begin to make generalizations about the lived experiences of study participants with the particular phenomenon.

There are numerous strengths to the phenomenological inquiry. Primarily, the qualitative nature of phenomenology allows the researcher to explore inconsistencies that are found in quantitative survey data. While quantitative data provides an account of the prevalence of a given phenomenon, qualitative analysis puts a human perspective on their experience with the phenomenon and allows for deeper and broader insights into particular situations or issues. In healthcare research, phenomenology can be used as an excellent tool to gain a deeper understanding with phenomena such as caring, healing and wholeness (Wojnar & Swanson, 2007). A better understanding of such phenomena can in turn, lead to the developments of new theories, and influence the nature of service delivery, policies and actions that reflect back on the voices of participants. (Tariq & Woodman, 2013).

Traditionally, the data collection strategy used in phenomenology is in-depth interviews. The output of an interview is a narrative account of the experience of the study participant with the topic of the research interest. The researcher then analyses the narratives to generate findings. Although there are as many as seven perspectives/types of phenomenology, the two main approaches are Husserlian (descriptive) and Heideggerian (hermeneutic/interpretive). The next paragraphs turn to the discussion of the two methods, potential selection guidelines for researchers, and the rationale for the chosen approach (with its analysis method) for this study.

Phenomenological Approaches

Phenomenology, as we know it today, originated in the twentieth century with Edmund Husserl (Husserl, 1962). According to Husserl, phenomenology concerns itself with the intentional structures of various types of human experiences including perceptions, thoughts, memories, and emotions. These structures in turn make up the awareness or consciousness which is always in reference towards a particular object or event (Reiners, 2012). Since Husserl's main insight depicts that consciousness is the condition that all humans experience, he developed descriptive phenomenology where every day conscious experiences are described while the researcher's preconceived beliefs, and judgments are withheld or bracketed (Reiners, 2012; Wojnar & Swanson, 2007). As such, to not influence the phenomenon at hand, to identify commonalities among research participants, and to be considered scientific, the researcher must engage in active listening/interaction, and strip away personal biases and prior experiential knowledge (Wojnar & Swanson, 2007).

In general, the Husserlian approach includes four steps: Bracketing (discussed above), intuiting, analyzing and describing (Hamill, & Sinclair, 2010). Intuiting refers to the researcher being open to listening about participants' experiences and gaining understanding and meaning from the interaction. Analyzing, refers to the process of coding the interviewed data and then finding common themes in the experiences. Finally, describing involves understanding, defining, and disseminating the findings of the research to applicable populations (Hamill, & Sinclair, 2010).

After his retirement, Husserl was succeeded by his former student, Martin Heidegger (Phenomenology, 2015). Heidegger established interpretive phenomenology by extending hermeneutics, to the philosophy of interpretation (Creswell, 1994). He studied the concept of dasein or "being in the world" (Wojnar & Swanson, 2007), rather than knowing the world. This concept emphasizes that a person's experience cannot exist outside the context of their values, family traditions, sociopolitical circumstances, and historical period. Heidegger proposed that our understanding of the everyday world is linked to our interpretation of it (Sloan, 2014). Unlike Husserl, who argued that biases/preconceptions should be bracketed to isolate the lived experience of a phenomenon, hermeneutic phenomenology rejects bracketing (Groenewald, 2004; Mapp, 2008; Wojnar & Swanson, 2007). Instead, this approach emphasizes co-creation of interpretations between the researcher and participant. As such, the meaning of the experience is determined from a blend of the researcher's knowledge/understanding of the phenomenon and participant-generated information (Wojnar & Swanson, 2007).

Guidelines for Choosing a Phenomenological Approach

Although there is no "correct" approach for choosing to explain a particular phenomenon, researchers should consider their personal cognitive style, and beliefs about how the findings of human experiences should be generated (Lopez & Willis, 2004; Wojnar & Swanson, 2007). For example, Husserlian (descriptive phenomenology) is more useful when the researcher wishes to identify universal (common) aspects of a phenomenon, that have never been fully studied or conceptualized. If the true description of the phenomenon can be identified via the descriptive protocol (involving bracketing), then any individual experiencing the phenomenon can potentially identify with it (Lopez & Willis, 2004; Wojnar & Swanson, 2007).

As opposed to descriptive phenomenology, hermeneutic (interpretive) phenomenology is more appropriate for researchers seeking uniqueness and differences in contextualized individual experiences (Wojnar & Swanson, 2007). Interpretive phenomenology is more rigid because it requires the researcher to have considerable knowledge of the phenomenon in order to co-create an interpretation of the experience together with the study participant (Mapp 2008).

Husserlian (Descriptive) Phenomenology and the Present Study

Home care services analysis, evaluation and planning can be addressed by Health Services Research (HSR). As opposed to biomedical research which highlights new discoveries in treatments, HSR utilizes social science perspectives stemming from the contributions of individuals and institutions involved in the actual delivery of health services (Sweet & Dogget, 2015). However, most importantly, it is HSR that underlies the development and implementation of policies and programs which impact the home care system. The different approaches to HSR provide varying insights into the questions of study. The qualitative approach is an essential component of HSR because it enables us to reach areas not susceptible to quantitative research (Al-Busaidi, 2008), for example, caregiver experiences. Phenomenology is a qualitative method that has been increasingly employed by HS researchers.

In the present study, the aim was to find commonalities among the voices of IFC seeking publicly-funded and/or privately-financed home care services. As such, the Husserlian (descriptive) phenomenological approach was an appropriate choice since it resonates well with researchers seeking similarities in human experiences, looking for patterns and proposing solutions for policies and actions. The descriptive approach is also more flexible in that the researcher does require prior knowledge of the subject matter in order to provide a detailed description of the phenomena from the narratives of those who have lived the experiences. Since very little research has been conducted in the home care setting that directly focuses on the experiences of IFC, descriptive phenomenology is more suitable then hermeneutic (interpretive). In addition, the hermeneutic approach assumes that all humans share contexts of culture, practice and language (Wojnar & Swanson, 2007). However, when it comes to IFC, the personal family structures/relations, cultural backgrounds and values vary, making co-creation of interpretations between the researcher and participant complex. Finally, as a physiotherapist, I felt that more wholesome descriptions of participant experiences would be possible if I were to bracket my own knowledge/preconceptions regarding the home care system. Since I did not wish to influence the voices of my participants, the descriptive approach was more suitable.

In terms of analysis (steps discussed in a later section), the Duquesne school of phenomenology follows the Husserlian approach. Researchers including VanKaam (1966), Colaizzi (1978) and Giorgi (1985) formulated three methods for data analysis based on descriptive phenomenology (Mapp, 2008). In all three methods, researchers search for commonalities in the voices of the participants as pertaining to the phenomenon of interest, and describe the experience through emergent themes. In terms of variations, Colaizzi's method differs from Giorgi's and Van Kaam's methods in that the final validation of the participants' experiences is provided by the participants themselves (Mapp, 2008). The question posed to participants would be "How do my results compare with your experiences?" If the true nature of the phenomenon is captured, then any participant should be able to identify their own experience within the descriptive results. The feedback from the participants is then used to make changes to the final findings. In VanKaam's method, the results of the findings are confirmed with expert judges as oppose to the participants (Mapp, 2008).

In contrast to Colaizzi and VanKaam, Giorgi's analysis relies solely on the researcher. Giorgi believed it to be inappropriate to ask either participants' or expert judges for validation of the findings (Lopez & Willis, 2004). To Giorgi, if meanings arise from one's consciousness, and all the necessary steps are taken to ensure that the descriptive protocol is followed (i.e., bracketing), then there is no reason to seek further affirmation (Beck, 1994). Instead, every reader of the study should become a critical evaluator of the phenomenon.

In the present study, Giorgi's method of analysis is employed. Since IFC are already taxed with time constraints and have kindly provided me with wholesome descriptions of their experiences with the home care system, I believed it would be inappropriate to ask for validation of the findings. In addition, since I am the sole researcher on this original study, and previous knowledge on this subject matter is highly limited, requesting external input from judges was not applicable.

Bracketing

Bracketing is a way of establishing the validity of the data collection and analysis process (Chan, Fung & Chien, 2013). Therefore, efforts should be made by researchers to put aside their pre-conceptions, beliefs, and experiences in order to accurately describe the participants' life experiences from the participants' perspective (Chan, Fung & Chien, 2013). Bracketing is steered by the thinking activity of reflexivity. Reflexivity involves the researcher's own self-awareness and the strategies they use to manage bias while maintaining sensitivity to the data (Chan, Fung & Chien, 2013). Such strategies include:

1. Mental Preparation: Maintaining a reflexive journal in order to write down thoughts, feelings and perceptions regarding a phenomenon. It allows researchers to examine their consciousness and become aware of their standpoint. Once aware, researchers can then adopt an open-minded attitude (Chan, Fung & Chien, 2013). In addition, a reflexive journal can be used to write down personal and caregivers' reactions as they describe the phenomenon.

2. Only conducting literature review to understand the background to the phenomenon of study. A thorough literature review should be delayed until after interviews are conducted in order to limit pre-conceptions (Chan, Fung & Chien, 2013)
3. Conducting semi-structured interviews with open ended questions allows for a flexible conversation and thus a deeper understanding into the phenomenon (Chan, Fung & Chien, 2013).
4. After researchers acknowledge that their own interpretations might influence the data analysis, they need to come up with measures to enhance the trustworthiness of the research. An audit trail is a strategy used to establish the trustworthiness of the qualitative inquiry. The audit trail enables an auditor to trace through a researcher's logic and determine whether the study's findings may be relied upon as a platform for further enquiry (Koch, 2006). Hence, audit trails make transparent the key decisions taken throughout the research process.

In general, health models have regarded the experiences of informal caregivers in a dismissive, homogenized manner while assuming that health, care, and social needs are the same amongst all (Armstrong & Armstrong, 2010). Unfortunately, these models obscure important personal inferences that can be contextualized through an insider's perspectives on providing care. These important perspectives are illuminated in this research study through a Husserlian phenomenological approach, allowing us to better understand the reasons and challenges for accessing, and utilizing public and private home care services.

Engaging in Self Reflexivity in the Present Study

As a physiotherapist, I came into this research with some knowledge of the workings of the home care system. Thus, employing a reflexive journal as a bracketing tool was extremely important for managing potential biases and establishing the trustworthiness of the research. Prior to commencing with the interviews, I had written down my own experiences (although minimal) working in the community. My thoughts, feelings, and presumptions regarding public and private home care services were outlined. This process allowed me to externalize and reflect on potential biases. By becoming aware of their existence, I was able to disengage and bracket my own knowledge and opinions.

During the interviews, I was entirely open to listening to the participants. Individuals were free to share their opinions and thoughts without interruption or judgement. My own thoughts were not presented or discussed during the conversations. Reactions of the participants as they described their experiences were recorded. In addition, a thorough literature review was conducted during the writing of this document and not prior to the interviews. Thus, limiting pre-conceptions and knowledge regarding the phenomenon. Finally, an audit trail (outlined in the *analysis* section) was used as a strategy to enhance the transparency of the research process and establish its trustworthiness.

Quantitative Approach and the Present Research

Survey Questionnaire

This study employs a quantitative survey questionnaire, with closed-ended questions, as a data collection tool to gather information about various characteristics of IFC (Appendix I), utilizing publicly funded and privately financed home care services. Questionnaires allow researchers to obtain numerical information pertaining to the topic of interest. In doing so, the researcher can determine factors which impact respondent's answers in qualitative reports. Questionnaires allow for simple, cost-effective statistical analysis which can then provide more insight in the lives of IFC.

Care Dependency Scale (CDS)

In addition to a survey questionnaire, this study employs the Care Dependency Scale (CDS) (Appendix II). This scale was not part of the semi-structured interviews. It was a separate task which participants completed. As a tool, it is used as an aid to assess basic patient needs and to measure the degree to which a person is care dependent on the informal caregiver (Dijkstra, White & Smith, 2006). The research project to develop the CDS began in 1994, in response to a lack of instruments for measuring patient care needs in Dutch nursing homes. The goals of the project were to create a tool that can be simple, short, reliable and valid for the assessment of dependency status. In 1997, this project went global as the European research group in healthcare (EURECARE), pushed for international co-operation in developing the CDS. Since both European and non-European healthcare colleagues were enlisted to aid in the development of CDS, the scale became utilized worldwide in clinical settings, community care, nursing homes, and residential home care services. The CDS is reliable and valid and has been determined to be an easy to complete tool by the caregiver or the care dependent individual in the home care setting (Dijkstra, White & Smith, 2006).

In this research, the relationship between CDS score and other variables (in both publicly funded and privately funded groups) such as hours spent caregiving, hours of services received, living location and working status of the IFC, are examined in order to determine significant correlations which complement the voices of IFC. In other words, it is used to shed light on how the level of patient needs impacts the experiences of IFC with home care services (in each public and private group) as per qualitative interviews. In addition, significant findings in the statistical tests between CDS and the above variables are used to compare experiences of IFC between those receiving publicly funded and privately financed services. For example, a significant relationship between care dependency and hours spent on caregiving in one group and a non-significant relationship between the two variables in the other group, will likely mean that dependency and associated burden of care is more pronounced for IFC utilizing services exclusively from the latter group.

The proxy version of the scale where informal caregivers answer the questions on behalf of the care dependent individual was used (Dijkstra, White & Smith, 2006). This is due to the fact that many of the care dependent individuals presented with cognitive impairment or severe disease states. The scale consists of 15 questions and normally takes less then 5 minutes to complete. Each question is scored from 1-5, with 1 representing complete care dependency and 5 representing almost complete independency. The total score is then the sum of all questions. A score of 15- 44 represents high level of dependency on the informal caregiver, 45-59 medium dependency and 60-75 low dependency. Increased care dependency in turn, may signify greater physical, psychological and financial challenges for IFC supporting the individual.

Understanding the term "Care Dependency" and its Operationalization

The term *dependency* is widely used in various disciplines. According to the Merriam-Webster's Dictionary (2020), dependency means something that is dependent on something else. It describes a relationship between objects or people where someone or something requires another to achieve a specific state or function (Boggatz et al., 2007). As such, dependency cannot exist as a stand-alone phenomenon and can only be understood in terms of a linkage.

One particular type of dependency is termed care dependency. Formally, “care dependency is a subjective, secondary need for support in the domain of care to compensate for a self-care deficit” (Boggatz et al., 2007, p.561). To be care dependent means that the individual requires compensative actions on behalf of healthcare professionals or IFC to fulfil their limitations (ie, dressing, mobility). Both the patient and the individual providing care should maintain a shared understanding of the concept in order to foster an appropriate and supportive patient/caregiver relationship.

In much of social psychology, and medical sciences, dependency as a term, denotes negative connotation regarding the characteristics of an individual or their environment (Heuvel Van Den, 1976). Yet, dependency by description does not always signify a negative state. For example, individuals who are dependent on their caregivers for their care needs, can remain satisfied with their situation if they receive the support required. Thus, care dependency is both a subjective and stigmatized concept requiring scrutiny. Health care professionals and researchers need to be mindful to not offend or belittle care recipients when using the term.

Mixed Methods Approach

The present study utilizes both the discussed qualitative and quantitative data in a mixed-methods approach. This approach has both strength and weaknesses. Its most prominent strength and underlying assumption is that mixed methods research can more comprehensively address the research questions of interest (Tariq & Woodman, 2013). This is especially true for complex, multifaceted issues such as health services interventions. The use of mixed methods can fill in the gap for each approach. While quantitative data provides an account of the prevalence of a given phenomenon, qualitative analysis puts a human perspective on their experience with the phenomenon, thus, allowing for deeper and broader insights into particular situations or issues.

In this research, qualitative data was used to capture (via interviews) the lived experiences of IFC with both publicly funded and privately financed home care services. In addition, quantitative data was used to analyze demographics and determine if there are significant relationships between particular variables. The quantitative findings may help explain and strengthen what is heard from the voices of IFC (qualitative findings).

Research Design Methods

Sampling and Recruitment

As the goal of this study was to explore in detail the situated experiences of IFC using publicly funded and privately financed home care services, this study utilized a purposive sampling technique for recruitment. Hence, individuals were selected for interviews on the basis of a shared trait—in this case, utilization of public and/or private home care services (Onwuegbuzie & Leech, 2007). For the inclusion criteria, all participants had to be English-speaking, and have been a primary unpaid caregiver to a family member in the last 36 months (2016-2018). They must also have either been receiving home care services funded publicly by the LHINs (or formerly CCACs) or paid out-of-pocket for PSW and/or nursing care from a home care agency or independent service provider. Individuals accessing a combination of public services supplemented by private services, were placed into the private group. Twelve interviews in each group were conducted at which point saturation was reached. Saturation of data collected is a frequently used criterion for when sampling should cease in a qualitative research study. The premise of saturation in a descriptive study such as this, is that no new themes emerge and there is high rate of duplication/recurrence of responses. Typically, when the last two interviews add no new information the researcher can then say the data are saturated (Ratcliff, 2008).

During recruitment, numerous home care agencies servicing the GTA and surrounding areas were contracted. A list of agencies was found on the Central Health Line online directory, and the Home Care Ontario website. Agencies were emailed with a description of the study along with a request for permission to distribute flyers to their service users (IFC). In addition, a study advertisement was posted via the The Family Caregivers' Support Network (FCSN) and on social media (i.e. Facebook) to groups that were made up of/relevant to IFC. Finally, snowball sampling was used to ask participants if they know of other caregivers utilizing public and/or private home care services. A number of LHINs contacted were not interested in assisting in this research. Regardless, a sufficient number of IFC for both the public and private group were recruited.

Data Collection and Interview Procedures

Data was collected in and around the Greater Toronto Area (GTA), of Ontario Canada. Due to the busy schedules of IFC, the interviews were conducted in the manner of choice by the participant- either via Skype, a WhatsApp video call or in the IFC's home. Recruitment took place over a period of approximately three to four months. Following recruitment, interviews were conducted from January 2, 2019 to February 28, 2019 and lasted approximately 30 minutes. Each interview was audio recorded, transcribed, and subsequently coded to assist with final analysis. Prior to the interview, participants were asked to complete and email back the consent form, the demographics survey and the CDS. Interviews were semi-structured in nature allowing for an open dialogue conversation on experiences with the guidance of pre-developed questions consistent with the phenomenological paradigm (Vagle, 2014).

This research received ethics review and approval by the Delegated Ethics Review Committee, which is the delegated authority to review research ethics protocols by the Human Participants Review Sub-Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. Special considerations for vulnerable populations need to be upheld in areas of sensitive research. Sensitive research is that which imposes on personal lived experience and involves issues sacred to participants, in this case, IFC.

As the sole researcher in this study I was committed to the highest ethical standards. These standards included honesty, empathy, and respect for all participants in the study. In selecting the methodology of phenomenology, I was committed to a reflective process which isolates the phenomena and their meaning from any potential preconceptions, beliefs and opinions. As such, I remained aware and dedicated to being flexible and open to truly learning about IFC experiences.

In addition, as a practicing physiotherapist, I am by profession trained to respect the needs of clients. I am also attuned to client comfort and can comprehend their experiences with the home care system. In order to avoid potential discomforts or conflicts of interest, my patients were not included in this research.

All participants were assured of confidentiality to the fullest extent possible by law. All documentation/recordings made in this study are not associated with personal or identifying information and do not contain the actual location of the participants. A code identifies each participant. Only the researcher has the code and corresponding participant identification.

Fictitious names were used in the analysis, themes and narrative descriptions in this research report. Names were removed from the master copy of the demographic survey and CDS after being coded. Quantitative information was analyzed using descriptive statistical methods. Individual narratives were integrated into the themes and dialogue narratives quotes using the fictional names, ensured complete participant confidentiality. All documents including: the interview recordings, transcription documents, demographic scales, CDS, and signed consent forms are kept in a locked file cabinet and password protected computer, accessible only to the researcher. These records will be kept for five years, as evidence to support the findings of the study.

The right to self-determination enabled a participant to withdraw at any time without penalty. Due to the possible vulnerability of the IFC being interviewed, they were free to end an interview at any time. IFC were not obligated to share any sensitive information which made them feel uncomfortable physically or emotionally. One individual was not able to complete the interview in a single session due to time constraints. Thus, the interview was conducted in two parts on separate days. Each interview was audio recorded. All audio recordings were time and date stamped and did not include identifying information. The audio was transcribed using an automated advanced speech recognition transcription software called TEMI. Since not all of the words in the interview are transcribed correctly, the software allows for the researcher to re-listen to any part of the interview and make correction directly on the document which can then be converted to Microsoft Word.

The interview methodology is subject to biases both on the part of the participant and the researcher. Biases, preconceptions, and attitudes can affect the data’s validity. However, descriptive phenomenology offers a means to address these complexities through the strategy of bracketing (Vagle, 2014). During the interview, participant's trust and comfort were valued. Being respectful and engaging in active listening was imperative to the dialogue (Yin, 2014). All of the participants reported that they enjoyed the interview process and felt worthy to have the opportunity to be able to contribute to this research. All 24 individuals recruited completed the interviews. Most IFCs requested the results of the research to be shared with them. Thus, upon the completion of this document IFC will receive a summary of the findings.

Qualitative Data Analysis

Analysis of phenomenology is focused on the deep understanding of the meaning of the description. This phenomenological study utilizes Giorgi's method of analysis to investigate the lived experiences of IFC with the publicly funded and privately financed home care system in and around the GTA. According to Giorgi (1970), there are five steps of phenomenological psychological analysis that are essential to any study utilizing a Husserlian perspective:

1. Assume the phenomenological attitude

This step involves bracketing on behalf of the researcher. Bracketing refers to the process of withholding any preconceived beliefs or judgements regarding the phenomenon of study (IFC experiences with home care), in order to reduce potential biases and preserve the data in its pure form as described by the participant. Bracketing allows the researcher to describe the participant's first-person perspective as per their conscious experience (as discussed in the methods section).

2. Read entire written account for a sense of the whole

This step involves reading the entire document multiple times. The purpose is to openly and freely read the text and try to generally understand the participant's language. There is no selectivity or attention to specific detail.

3. Delineate meaning units

The purpose of this step is to read the text over again and to discriminate the meaning units from the narratives. Meaning units are segments of the description of experiences that are relevant to the phenomenon of study (experiences with home care). They can be short (one sentence) or long expressions, as long as they lend purpose to analytic reflection that helps to answer the research questions.

4. Transform the meaning units into psychologically sensitive statements of their lived-meanings

This stage of analysis involves transforming the meaning units into third-person language while maintaining the context of the meaning described by the participant. The process of transformation takes place through Hussler's procedure known as imaginative variation. Imaginative variation is performed by the researcher by varying the frame of reference (Giorgi, 2009). By taking each meaning unit individually, the researcher dwells with it and reflects on what is being psychologically expressed through it, thereby, detecting and revealing the psychological meaning in the data.

5. Synthesize a general psychological structure of the experience based on the constituents of the experience.

In this final step, the constituents of the experiences are determined by inspecting the transformations of all participants for convergent meanings. The integration of insights gained through reflection of meaning units allows the researcher to see the shared meanings of the participant's experiences pertaining to the investigated phenomenon. In the present study this is the experiences of IFC with home care in Ontario (public and private).

Qualitative Analysis using Nvivo 12

This study utilized QSR International's Nvivo 12 qualitative data analysis software (2018) for organizing the research data. Nvivo was developed for researchers working with rich textual and multimedia information, to enable them to systematize and analyze non-numerical study data. The most current version of the software, Nvivo 12, is used by academic, governmental, and commercial organizations in various fields of activity, including social sciences such as psychology, sociology, medicine and phenomenology studies. The basic data, used for Nvivo are text and video messages. The software allows users to classify and sort information, and explore the relationships in data. Such a wide range of functions makes it possible to use Nvivo 12 in different methodological paradigms, including phenomenology, which requires a large amount of information to be analyzed (Sohn, 2017). With the help of the software, the researcher or analyst can identify trends and themes as per the questions of study. In general, the benefits of using a qualitative data management software include time saving, ability to import and sort large amounts of data, and potential to provide greater validity and auditability of qualitative research (John and Johnson, 2000). Nvivo's capabilities to handle large files, code textual data, analyze trends and themes between data points made it an appropriate tool for use in this research.

Implementation of Nvivo in Giorgi's Method of Phenomenological Analysis

The goal of a phenomenologically oriented study used by Giorgi (2009) is to obtain clear, accurate, and systematic descriptions of various aspects of human experience. Phenomenological research, implemented by Giorgi is focused on the disclosure of the structure of a particular experience, associated with a certain subject, situation, event, or some aspect of human activity (Giorgi, 2009; Gibbs, 2003). Thus, the use of Nvivo is suitable to analyze the data, retrieved from the person, in this case, the IFC, who is under investigation. The data are presented not in the form of numbers and statistics, but in the form of oral descriptions, and/or voice recordings, regarding the experience of the phenomenon of study (Gibbs, 2003). As soon as the researcher has obtained information about the experiences of the person under investigation, Nvivo may be implemented to analyze the data and group the most frequently used and mentioned experiences into themes. Nvivo software provides descriptive results; therefore, there is no need to use additional tools for data analysis (Gibbs, 2003).

Taking into account that Nvivo accommodates a range of functions and tools to analyze data, the researcher or analyst can identify trends and cross-examine information in numerous ways. Phenomenological descriptions in Giorgi's method are as non-theoretical and concrete as possible. Phenomenological method, offered by Giorgi is against the non-obviousness and randomness of theoretical constructions (Gibbs, 2003). The phenomenological method is qualitative, which is based not on numbers and numerical data, but on observations, texts and review of previous literature known about the phenomenon. Since Giorgi's method presupposes the use of description in dealing with phenomenological research, Nvivo 12 has been a useful tool for analysis in the present study.

The data analysis portion of this study commenced once the interviews have been transcribed and the text has become the pragmatic evidence to be analyzed. Giorgi's (1970) principles of data analysis described in the previous section were then followed. The researcher first imported the participants' interview transcripts as a new project created in

Nvivo 12. As suggested by Giorgi (1970), transcripts were read in their entirety multiple times, in an attempt to gain an understanding of the text as a whole. The software was then used to code individual interviews into meaning units and condense codes into categories based on recurrent patterns. From there, analysis was conducted to determine the themes in IFC experiences with the home care system based on the research questions.

Audit Trail in Qualitative Phenomenology Research

Audit trail is a qualitative strategy, implemented in research to institute the confirmability of the findings of the research study (Carcary, 2009). Confirmability is about establishing that the research findings and conclusions are based on correct and unbiased participants' responses, and not on the suppositions, preconceptions and biases of the researcher (Carcary, 2009).

The biggest advantage of the audit trail in qualitative research is that it is able to prove that the findings and results of the research are based on the narrations of the participants. Audit trails describe the way the researcher collected and analyzed data in a transparent way. In addition, an audit trail is an excellent strategy to apply because it is inclusive and can enable the researcher and readers to think critically about the decisions made. In the phenomenology paradigm, this strategy is effective, because it ensures a recursive process (the researcher repeatedly goes back through the data and keeps track of their decision-making process). Finally, audit trial is an excellent tool to use in qualitative research as it helps to be sure that the data, used for decision-making are bias free and authentic (Carcary, 2009).

Audit Trail in the Present Study

The audit trail consists of the following steps conducted during the research:

1. Each interview was audio recorded. All audio recordings were time/date stamped and saved on a password protected computer in two folders: *audio interviews- public* and *audio interviews-private*.

2. Each audio was transcribed using an automated advanced speech recognition transcription software called TEMI. The transcripts were downloaded and saved in two folders: *transcribed interviews- public* and *transcribed interviews-private.*

3. In Nvivo 12, a new project entitled *Caregiver Experiences* was created. The transcribed interviews were then imported into two generated folders*: Public Homecare* and *Private Homecare.*

4. Each interview was carefully read numerous times and segments of the description of experiences that are relevant to the phenomenon of study were highlighted and coded into meaning units. In Nvivo 12 the meaning units are called Nodes. For example, the following segment of a narrative: "what is the frustration with the system, is the fact that nobody tells you what you are eligible for or what you could possibly be entitled to," was coded into the node: *Inadequate Information.* Another segment: "My identity, I've lost my identity. I can feel comfortable perhaps just leaving her for an hour or so if she's in bed in the afternoon, sleeping or whatever. But that's about the extent," was coded into the node: *Loss of Self.*

5. Each Node created in Nvivo 12, was at the same time placed into a category or theme. In the software, this was done by grouping the Nodes into Sets. For example, nodes such as *Inadequate Information*, and *Delays in Response* were grouped into the theme of *Difficulty in Finding Out About and Accessing Services*. Nodes such as *Loss of Self, Financial Capabilities, and Limited Respite Time* were grouped into the theme of *Personal Challenges of Informal Family Caregivers.*

The Nvivo 12 software itself produces a saved step-by-step process of how the narratives, nodes and themes are organized. An auditor wishing to confirm the findings of the research simply has to access the project and inspect the transparent decision-making process.

Quantitative Data Analysis

Statistical Testing: Spearman's Correlation

Spearman's correlation coefficient is a statistical measure of the strength and direction of a monotonic relationship between two ranked variables (Statstutor, n.d). A monotonic relationship is one that either never increases or decreases as its independent variable increases. The Spearman rank correlation coefficient, r_s, is the nonparametric version of the Pearson correlation coefficient. The data must be ordinal, interval or ratio. Spearman's returns a value from -1 to 1, where the closer r_s is to (+/- 1) the stronger the monotonic relationship. As it a non-parametric statistic, there is no requirement of normality (Statstutor, n.d). Correlation is an effect size used to verbally describe the strength of the relationship, using the following guide:

- .00 - no correlation between variables
- .00-.19 — very weak
- .20-.39 — weak
- .40-.59 — moderate
- .60-.79 — strong
- .80-1.0 — very strong
- +1- perfect positive correlation
- - 1- perfect negative correlation

In the present study, Spearman’s correlations were used to determine the relationships between care dependency score (ordinal), hours spent caregiving (ratio/continuous), hours of public care (ratio/continuous) and hours of private care (ratio/continuous) for 12 participants in each public and private group.

Since hours spent caregiving is ordinal data, the Spearman’s correlation was an appropriate statistical test.

Fisher Comparison of Correlations Test

This test is used to assess correlations retrieved from different samples against each other in order to determine if there a significant difference in the correlation of both cohorts (Lenhard & Lenhard, 2014). In the present study, this test is run between the correlation coefficients found in CDS and hours of public care received and CDS and hours of private care purchased. This test indicates if there is a significant difference in responsiveness to care needs between the two samples.

Mann Whitney U Test

The Mann Whitney U Test is a non-parametric test used when there is a continuous level variable measured for all observations in two groups and the researcher wants to test if the distribution of this variable is different in the two groups (The British Academy, n.d).

In the present study, I am looking to investigate whether there is a difference between the CDS (continuous variable) of the client and the working status of the IFC (working or not working). As well as CDS and the living status of the IFC (living with client or not)- for both public and private groups.

Chapter Six
Research Findings

Introduction

This chapter reports on the real-life experiences of IFC with publicly funded and privately financed home care services in and around the GTA. The results section begins with quantitative analysis followed by qualitative findings which include participants' narratives and consistent themes. Within each section, public and private findings are presented separately. The organization of results in this manner enables a neat and accurate account of the participant's situation in relation to their caregiving role. The research questions are addressed at the end of the chapter based on the findings.

Themes are fundamental to the experience and understanding of the whole phenomenological dimension. Themes provide insights into how individuals make sense of experiences in their lives and, the meanings they assign to these experiences. Themes emerge from the data in the narratives of the individuals describing their experiences with a particular phenomenon. Themes are used as a means to arrive at a "fuller description of the structure of a lived experience" (van Manen, 1990, p. 92). In qualitative research, themes are generated from the data in the primary sense of the word, *datum*, meaning something given or admitted by the participants themselves (Bermen, 1994; Mish, 2002). In the present study, the themes provide a deeper understanding of the experiences of IFC with publicly funded or privately financed home care systems in Ontario.

In phenomenology, the participants' interviews are the raw narrative data (Gorgi, 2009). In this study this includes participants' stories about their everyday lives, their experiences as IFC and their experiences with the home care system. Phenomenology also includes a commitment to bracketing, and reflection, which contributes to the purity of data of narratives and consistent themes. As previously discussed, bracketing is central to descriptive phenomenology (Giorgi, 2009). Bracketing activities begin even prior to the initiation of research activities. The literature review on the background to the topic sought to nullify the effects of any preconceived beliefs or judgements regarding the phenomenon of study in order to reduce potential biases and preserve the data as described by the participant.

Publicly Funded Home Care- Quantitative Findings

Table 2. describes the characteristics of the IFC in the public group in relation to their caregiving role.

Table 2. Caregiver Characteristics- Public

Name	Age	Living with Client	Client Diagnosis	CDS	Hours spent on Caregiving/day	Working	Income	Relationship to caregiver	Hours of public care/wk	Caring after others
Lily	55-64	Yes	Parkinson	45	12 to 14	No	NR	husband	7	No
Nelli	35-44	Yes	diabetes	55	4 to 6	Yes	50-59	daughter	40	Yes
Maria	55-64	No	dementia	60	0 to 2	Yes	NR	mother	26	Yes
Emma	55-64	Yes	severe CP	15	14 +	No	50-59	son	21	No
Jill	55-64	Yes	wounds	53	12 to 14	No	NR	husband	5	Yes
Samantha	65-74	Yes	stroke	45	4 to 6	No	NR	mother	1	Yes
Dina	55-64	Yes	Alzheimer	57	6 to 8	Yes	NR	mother	2	Yes
George	55-64	Yes	palliative cancer	19	10 to 12	No	NR	wife	21	No
Debra	65-74	Yes	stroke	41	4 to 6	No	NR	mother	17.5	Yes
Mia	45-55	Yes	diabetes	66	0 to 2	Yes	50-59	mother	5	No
Rachel	65-74	Yes	dementia	51	4 to 6	No	30-39	husband	3	Yes
Flora	65-74	Yes	dementia	18	14 +	No	NR	husband	14	No

*NR- Not Reported

Twelve participants (IFC) were interviewed in the publicly funded home care group. A fictitious pseudonym is assigned to each caregiver to protect anonymity. The individual being cared for, is referred to as “client.” Of the participants, eleven are female and one is male. The majority are of Caucasian background. Caregivers are all family members either caring for their spouse, parent or child with a disability. Of the twelve participants, only one is living separately from the client. This study captures a range of diagnosis with dementia being the most common condition requiring home care supports. Of the twelve participants, seven are also caregivers to other individuals (not receiving home care). Eight participants report having their own health concerns. Two of the clients reside just outside of the GTA and all others reside in the GTA. All IFC report engaging in the following duties: personal care, food preparation, medical care, mobility assistance and transportation. Four participants are employed. Participants were not obligated to disclose their incomes and only four did. Although I had hoped for more data on income for the purposes of quantitative analysis, this information is still valuable as complementary to the voices of IFC, most of whom cite financial reasons for not seeking privately financed home care (discussed below in the qualitative findings section).

Spearman’s correlations are used to determine the relationships between care dependency score, hours spent caregiving, and hours of public care for twelve participants receiving public home care. There is a strong, negative correlation between the care dependency score and hours spent on informal caregiving, which is statistically significant ($r_s(12) = -.724$, $p = .008$). No other statistically significant correlations emerges. N=12 for all tests. The *p* values for non-significant tests are as follows:

Hours spent on caregiving and hours of public care received (p=.934)

CDS and hours of public care received (*p*=.592)

Those IFC in the public group who are currently working are looking after clients with significantly higher CDS (less dependent) than those who are not working (U=0, *p*=0.004). Those looking after clients with high care needs are not employed. As such there is a strong relationship between CDS and work status in the public group. There is no relationship between CDS and living status of the IFC.

Quantitative Findings Interpretation and Significance- Public

The results demonstrate a significant correlation between the hours spent on informal caregiving and the care dependency score. The lower the care dependency score, the more needs a client presents with, and the more time the informal caregiver dedicates to their role. As such, the lower the score is for the clients in this study, the more hours the informal caregiver dedicates to them.

There is no correlation between the care dependency score and the hours received from the publicly funded home care system. Thus, it appears that the needs of the client are not taken into serious consideration when hours are allocated. This finding is consistent with my hypothesis where I expected the linkage with underfunding in the current home care system and the challenge in accessing sufficient care hours. In addition, this finding is relevant to the study conducted by Grant & Church (2015) where, there was no uniformity among CCACs on the criteria to determine eligibility for care. The scoring used to evaluate the number of hours a client may need, is funding dependent, subjective and not in accordance with true physical/psychological needs.

Furthermore, there is a significant relationship between working status of the IFC and CDS score of the client. IFC looking after clients with high care needs were not engaged in paid employment.

These findings have serious implications for IFC. Caring for clients with varying levels of needs, and not receiving sufficient external support from the publicly funded home care system, can result in physical/psychological burnout and financial vulnerability. IFC spend many hours of their day engaging in direct and indirect care tasks. They do not receive opportunities for respite and are not able to maintain employment. It becomes an ongoing pattern, where inadequate home care supports, prevent individuals from engaging in paid labour, in turn, hindering the ability to hire private care for respite breaks, which negatively impacts health.

Privately Financed Services- Quantitative Findings

Table 3. describes the characteristics of the IFC in the private group in relation to caregiving role.

Table 3. Caregiver Characteristics- Private

Name	Age	Lives with Client	Client Diagnosis	CDS	Hours spent on Care/day	Working	Income	r/l to caregiver	S/P public hrs	Hours of public care/ wk	Hours of Private care/ wk	Caring after others?
Rose	45-54	No	Dementia	32	2 to 4	Yes	NR	father	No	0	24.5	No
Darla	55-65	No	Severe Autism	23	4 to 6	Yes	80-89	son	No	0	30	No
Vicky	55-64	No	dementia	47	2 to 4	Yes	NR	father	No	0	41	No
Danna	55-64	No	dementia	64	2 to 4	No	90-99	father	No	0	4	Yes
Holly	55-64	No	blind	55	2 to 4	Yes	NR	mother	Yes	1	112	No
Fred	55-64	Yes	heart condition	18	6 to 8	No	125-149	wife	Yes	28	98	No
Amanda	55-64	No	dementia	20	2 to 4	Yes	150+	mother	No	0	168	No
Sharon	55-64	No	dementia	15	8 to 10	Yes	NR	parents	No	0	168	Yes
Linda	35-44	Yes	severe arthritis	36	4 to 6	Yes	90-99	mother	Yes	20	10	Yes
Eleanor	55-64	No	colongeal cancer	68	2 to 4	Yes	80-89	Husband	Yes	6	21	Yes
Betty	55-64	Yes	dementia, blind	61	14+	Yes	NR	mother	Yes	10	6	No
Mark	35-44	Yes	Endo cancer	55	4 to 6	No- on disability	NR	mother	Yes	2	2	No

*NR- Not Reported

Twelve participants (IFC) were interviewed in the privately financed home care group. A pseudonym is assigned to each caregiver in order to protect anonymity. The individual being cared for, is referred to as “client.” Of the participants, ten are female and two are male. The caregivers are all family members either caring for their spouse, parent or child with a disability. Of the twelve participants, eight are living separately from the client. This group captures a range of diagnoses with dementia being the most common condition requiring home care supports. Of the twelve participants, four are also caregivers to other individuals (not receiving home care). Four participants report having their own health concerns.

Six participants are supplementing public home care with private services. Seven are receiving services from an agency and five hire an independent service provider. Of the twelve caregivers, three are paying for the private care of the client, three are sharing the expense with the client (“shared”), and six of the clients are paying in full using their own resources. One client resides in Windsor, Ontario and all others in the GTA. Most caregivers report engaging in some of the following duties: personal care, food preparation, medical care, mobility assistance and transportation. Nine participants are employed. Participants were not obligated to disclose their incomes and only six did. Although I had hoped for more data on income for the purposes of quantitative analysis, this information was still valuable as complimentary to the voices of IFC, all of whom cited having the monetary resources to purchase private home care services (discussed below in the qualitative findings section).

Spearman’s correlations are used to determine the relationships between care dependency score, hours spent caregiving, hours of public care, and hours of private care for twelve participants receiving privately financed home care. There is a strong, negative correlation between the care dependency score and hours of private care purchased, which is statistically significant (r_s (12) = -.698, *p* = .012). No other statistically significant correlations emerge. N=12 for all tests. The *p* values for non-significant tests are as follows:

Hours spent on caregiving and hours of public care received (*p*=.138)
Hours spent caregiving and care dependency score (*p*=.278)
Hours spent caregiving and hours of private care (*p*=.820)
CDS and hours of public care received (*p*=.592)
Hours of public care and hours of private care (*p*=.332)

There is no significant difference in CDS and working or living condition of the IFC in the private group as per Mann Whitney U Test. In other words, there is no relationship between the working/employment or living status of the IFC and the client's needs.

The Fisher Comparison of Correlations Test was run between the correlation coefficients found in CDS and hours of public care received (*r*= -.698) and CDS and hours of private care purchased (*r*=-.172).

Fisher Test (test statistics Z) = -1.463, probability *p*= 0.072.

This test indicated that the magnitude of differences in the correlations approaches significance. As such, a real difference in the relationship between need and care is seen between public vs private delivered care.

Quantitative Findings Interpretation and Significance- Private

The results demonstrate a significant correlation, between the care dependency score and the number of private home care hours purchased. In other words, clients with greater care needs are receiving more hours of services paid for out-of-pocket. Unlike in the public group, care dependency score does not correlate with the number of hours spent on caregiving or the living or working conditions of the carer. This is likely because hours (and resultant met needs for care) are absorbed by hired service providers as opposed to the direct care conveyed by IFC. This finding is consistent with my hypothesis where I expected to see less of a burden of care on the IFC in the private group than in the public.

Within the broader political and economic context these findings point to the illusion of *choice,* a primary goal of strategic neoliberal reforms which seek to minimize public supports (McGregor, 2001). Those individuals who are able to access privately financed care and make decisions regarding the services they require, are able to obtain respite, engage in paid employment (all except one were employed), and live separately from their loved one. Such conditions are favorable to health because they result in less stress and more flexibility in meeting the needs for care. Conclusively, these findings signify a system filled with inequities which privileges IFC who have *choice* vs. those who rely solely on the crucial but underfunded public home care system.

Table 4. identifies the distribution of CDS scores, means and standard deviations in public and private groups.

Table 4. Distributions of CDS Scores

	Publicly Funded Group (N)	Privately Financed Group (N)
Low CD (60-75)	2	3
Moderate CD (45-59)	6	3
High CD (15-44)	4	6
Mean CDS Score	43.8	41.2
Standard Deviation	17.4	19.5

The chi-square statistic is 1.6 with p=0.45; the result is not significant at p< 0.5. Since there is no difference between the CDS in the public and private groups, comparisons of qualitative findings will be discussed.

Publicly Funded Home Care- Qualitative Findings

Participant Narratives

This section presents the individual stories of IFC receiving publicly funded services. Most participants refer to *CCACs* in their stories, as the amalgamation with the LHINs only happened in mid 2017. Since the participants have been caregiving for prolonged durations, they are either used to the previous structure or unaware of the change. To protect identity and at the same time give a sense of the persons in the experiences, fictitious names are assigned to the participants. Two IFC are randomly chosen for full narrative presentation.

Flora

Flora was a caregiver for her husband who developed progressive dementia at the age of 72. For a full year, she provided 24/h care, and barely slept. She describes having no time for anything other than care tasks, with no initial external help. The family doctor did not refer to CCAC, her daughter who was living in California, did the research and found out about CCAC services. It took a few months to finally receive care. According to Flora, CCAC were waiting for her husband to get more "paralyzed". They were saying that he needed to demonstrate more of a decline before they could initiate services. "It was a very horrible time for me. I needed the help. I was getting nothing. They thought they will bring help when he's so bad. That's not to say, but I guess, why do we have to wait until he gets so bad? If he's that bad, he should be hospitalized." Finally, when she did receive PSW services, it took time to have a consistent individual. "She was okay, but she was only feeding him and giving him a shower, nothing more. Not much help, I would say now. This is one of the biggest hurdles, I think, you need more help."

In terms of help, Flora would have liked the PSW to provide more comfort to her husband, develop a rapport. She would have also liked her to warm up the food prior to feeding him. In addition, the PSW was always rushing to get in and out of the door in order to make it to her next patient.

> They have only limited time, so they have to rush. Sometimes they don't focus on what they're doing. Sometimes they're trying to feed him fast, and because he was declining, it was very hard for him to swallow. They were not waiting, so he'd finish fast and swallow fast and bite. Sometimes he just began throwing up. I was watching it. He was taking time to swallow and break the food down, but they weren't interested. It's not their fault, but that's what's happening a lot, and it was hurting.

In addition, the PSW was only coming in one hour in the morning and one hour in the evening. Flora would have been grateful with more hours, but they were not offered.

> At least a minimum, two hours in the morning, two in the evening, because this is nothing. This is nothing compared to what I went through and how my husband's situation was. This is not good enough at all. Trust me, I was not having time to breathe. I even forgot to breathe. I don't know if I'm breathing. No time for myself. I stopped going for my physio and I gave up everything.

Flora had no respite from her caregiving role. Even when the PSW did come, she had to watch over to make sure that proper care was provided. On the whole, Flora feels that there is too much difficulty in accessing care, there is too much inconsistency and not enough hours allotted to those who are struggling.

Lily

Lily has been a caregiver for her husband with progressive Parkinson's for the last eight years. She describes her life as a routine, that is structured around her husband's care.

> His morning starts at 9:00am. It's usually morning things like wash his face, change his diaper, and maybe some other stuff that takes sometimes 30 minutes, sometimes 40 minutes. After that, around 10:00am, he eats breakfast, plus he's having his medications. Then he has some rest, maybe an hour. After that, if he's in a good mood or in a good condition, we can do some exercises for 10-15 minutes. He has different kinds of exercises to stretch his legs, to stretch his arms. At 12:00pm he has his lunch. The lunch is usually around half an hour, maybe 40 minutes. Now we have PSW coming for one hour. So 12:30, he's coming. He's doing, sometimes a shower, sometimes it's just some other kind of exercises, or if weather is permitting, he can go for a walk, for 10 minutes. After 1:00pm, he's having his day naps, sometimes it's hour, sometimes it's two hours. Around 3:30pm is his snack time. Sometimes we have some other activities like maybe exercises, or we have a puzzle. Sometimes during the night, he doesn't sleep fully. He can wake up every two hours.

Lily initially found out about CCAC from her physician. She called and a case manager came to assess her husband. She notes that she did not have trouble accessing CCAC because she received advice from her physician but the main problem they currently have is the hours.

> Before we had three to four hours per day, now we have just one hour a day. They (CCAC) said that it's something from the government, they cut the services. The first thing they cut are the hours for the patient. This one hour of PSW it's not like 60 minutes. It's mostly 45 minutes because he has time to come in and he's supposed to have time, like 15 minutes, to reach to the other client.

Lily also had some challenges with the PSW's coming in from the agency. After three years, they finally have a consistent PSW, that her husband likes.

> Before we had some difficulties with PSWs. I would say behavioral stuff. For me, it's not appropriate when someone comes for the first time to your house and starts searching for something. Oh, what do you have? What is this?' Something like that. One was not very responsible for his work, it's a lot of different stuff. We had a lot of different types of PSWs. Finally, Anthony came and he is okay, he's a nice guy, very professional, very responsible with what is he doing.

During her husband's nap or when the PSW comes in, Lily does not get a break.

> One hour is just for his PSW, so if there is time, I can do some preparations for the evening, like maybe make some food/snacks. I have a lot of stuff to do during these nap breaks. I need to laundry his stuff. I have to change it every day, because sometimes it's soiled, sometimes it's with some drops of urine on the bed. If he has problem with his bowel movement, sometimes it takes more than hour, to do all this stuff. After bowel movement, I have to clean him, I have to wash him.

On the whole, Lily would like to get more hours, ideally four per day. She would also like to get a specialist to work with her husband including a speech language pathologist and a physiotherapist, which are not being offered. "Financially, we can't pay for these private services because prices are not so cheap." Personally, Lily describes her life as the following:

> Now my life, my own life, my personal life belongs to my husband. I have to give up my own things, like I have some hobbies, I have some things that I like to do for myself, like maybe read books, some stuff which just needs time.

Consistent Themes

The following seven subsections present the consistent themes described by participants pertaining to their experiences with publicly funded home care services. The voices of participants who supplement publicly funded services with private are also included in areas where they speak of their experiences with public care. The themes are supported by the participant's own words from the interview transcripts in order to best describe the experience.

Theme 1: Caregiving is a routine

Participants describe caregiving as a structured routine. The scheduling of daily activities provides both caregivers and clients with a sense of order which is extremely important for their well-being. Elderly individuals and those with disabilities require structure for care activities from both home care services and the caregiver, in order to avoid physical discomforts and emotional upsets. Caregivers require routine in order to plan their daily lives which may include work and other in-home demands such as caring for other family members.

Emma provides 24/h care to her son with severe Cerebral Palsy. She describes her experience as a constant journey in which she must always stay attentive and alert. Any changes in routine for her son leads to severe anxiety and is best avoided.

> First thing in the morning I have to clean him after he poops at night. Then give him a shower. Sometimes I stop him and give him a few minutes so he can enjoy. He can hold the shower head. Then I transfer him and do things like shave and dress him. Then after that I have to transfer him again to this stroller. He wants to be pushed around. In winter time, we can't go outside. We are just wondering back and forth in the hall, the Condo. Then the worker (PSW) comes for two hours. Meantime, I can clean the house, I can have breakfast and it goes by very quickly. When he comes back again its feeding, then its changing his diaper. Sometimes he wants to lay down a bit, if he's getting tired. He is anxious and has mood swings. We go again for a short walk.

George is a caregiver for his wife, who has palliative cancer. He describes his experience as a 7 day a week, consistent routine. In this manner, he makes sure that her needs are met.

> I get up usually around 9:00am and a PSW gets her up. Probably about a quarter to 10:00 am she's ready for breakfast. Completes her breakfast around 10:30am. She's up in the wheelchair until 12:30pm or one when the PSW leaves. She's goes back to bed and she's there until five o'clock at night. PSW comes around seven o'clock.

Jill is a caregiver for her husband who developed open wounds as a result of diabetes. She describes her experience as follows:

> I need to help him get coffee in the morning and his breakfast. Get him ready. Like today, I showered him because the nurse was coming. She changed the bandage. We have to have a

> shower before the bandage gets changed. The PSW doesn't come until 10 o'clock. Then I can leave him for a little bit if I need to go out, but he's had more falls lately, so I don't go too far. I make his meals and of course, I clean up after.

Theme 1. Summary and interpretation

The experiences are presented by IFC who reside with the client

(majority in this sample). They depict fairly rigid daily routines. While instilling order in the lives of caregivers and clients, they leave little opportunity for respite. Even during the time when home care services are being provided, caregivers typically engage in other household tasks such as cleaning and cooking. The day revolves and is structured around the needs of the loved one.

Theme 2. Difficulty finding out about and accessing services

IFC who have previous knowledge of the workings of the LHIN either through their work environment or previous experience are able to get connected. However, numerous caregivers requiring the support of the publicly funded system either do not know of its existence, or do not know where to turn to obtain the services. Interestingly, caregivers of clients who are hospitalized and required discharge with home care, aren't always given a referral to the LHIN via the hospital's network.

According to Eleanor, "what is the frustration with the system, is the fact that nobody tells you what you are eligible for or what you could possibly be entitled to." Linda, a mother of two, and caregiver of a parent states:

> One of my sisters mentioned CCAC and then I started looking it up online and it took me I think a few months just to connect. It's not very straight forward. You would think that's something the doctor would have in their office and they will provide you with the number. No, not the case at all. I was doing everything. I was taking her to the bathroom. I was struggling in the middle of the night and I had no idea that there were such things as adult diapers. A coworker, a male coworker told me about it.

Emma, received very little information from the hospital in which her son was regularly admitted. “I got some information from the hospital but more about it I got from other parents. The government actually doesn’t seem like they want you to know.”

Likewise, Flora found it difficult to obtain services for her husband. Her daughter who resides in another country, had asked various individuals in the GTA about potential services in the city. The family never heard of CCAC and but once they found out, it took time to connect and obtain PSW care. “It’s a couple of months. It took long to reach. They were just waiting, letting him get more paralyzed.”

Occasionally, clients admitted to hospital have a simpler transition to home care when the coordination of services is offered and completed on site. Mia’s mother has been in and out of the hospital for many years as a result of diabetes. She has an amputated leg and is not able to be independent in the home. Home care services were set up prior to discharge.

Theme 2. Summary and interpretation

Funding for publicly funded home care is limited. As such, information regarding the existence of services and how to access them, is not readily available. IFC, who do not receive a referral via the hospital system, end up finding out about services from other individuals in the community. It can then take a long time to connect with the LHIN and to initiate care. Meanwhile, it is the IFC who are providing all the support to the client.

Theme 3. Complexities with changing regions/LHINs

There are instances where clients are admitted to a hospital in one region but live in another and require discharge with home care services to their LHIN. There are also instances where families move from one region to another.

Dina’s family moved from one CCAC region to another. “You have to go through all the paperwork again and you have to start from scratch.” Similarly, Emma had relocated between CCACs. “It’s an administrative mess. We have been receiving services from our local CCAC for years but when we moved, we had to start all over again with the explanations. It was a new assessment and it took time to sort everything and get the care.” In some situations, a poorly managed referral to another LHIN can have serious consequences as in Eleanor’s situation.

> Sunnybrook was one CCAC, we lived in another CCAC and so the, referral got dropped between the CCAC’s. I knew that when my husband was being discharged on the weekend, if they didn’t come the same day, they weren’t coming. So, the next day we called as his wound became more infected because there was nobody to do the wound dressing. It took two days to get their act together and the supplies were incorrect and it was on the third day the proper supplies arrived. The CCAC in North York was providing 100% wet dressing twice a day for my husband. The minute we went down to south western Ontario, they didn’t have money in their budget for that. Their focus was to teach somebody to do their own wound dressing from there. We got the minimum amount of hours, the ones where I’m saying, we had to fight for. Let me be very, very clear. We had to fight for that dressing.

Theme 3. Summary and interpretation

According to the LHINs, moving between regions should be seamless.

> Simply notify your Care Coordinator of your upcoming move – we’ll make sure your new Local Health Integration Network is expecting you and is ready to continue your services. You will meet some new people when you transfer to a different region, so you might anticipate a short time of adjustment while you settle in to your new home. But rest assured that you will receive the same high quality of care you have always received. And yes, your records and files will be accessible by your new Care Coordinator. (Home and Community Care, 2017)

Unfortunately, caregivers note that transitioning between regions is not a smooth process. They report complexities with the transfer and accessing home care services locally. Referrals get dropped and new case managers are not being assigned client files with information regarding previous care. Since each LHIN has their own budget, a new assessment is conducted in order to determine eligibility for services. The Resident

Assessment Instrument-Home care, is once again completed. However, since its scoring is not uniform, applicants may qualify for alternate hours of care, unlike in the previous region. On the whole, the organizational disruption and inconsistency between LHINs can be detrimental to the health of individuals and challenging for the caregivers.

Theme 4. Care is case manager, agency and worker dependent

Participants report a range of experiences with different case managers, home care agencies and workers. Rachel states, “I think I went through, two or three care coordinators under CCAC as they were transferring into LHINs. The last care coordinator, hopefully will get to continue with us. It’s an interesting journey. I think this last person has a little bit more compassionate and sensitivity.”

When her son was young, Emma had a terrifying experience with the PSW but was too afraid to complain in case she would lose her hours.

> My son was sitting in a highchair and I was in the kitchen. The PSW who fed him was supposed to take him and put him in the stroller. She took away the tray and went somewhere to put it and left him. He almost fell face down and at the last moment I caught him. I got so scared. I didn’t want to report that because I was afraid I would lose those four hours.

In addition, Emma’s son previously had a consistent PSW from one agency but for some reason, the CCAC decided to switch her to a different agency. The communication with this agency is more complicated and the workers often change.

> Previously my son got two years with the same worker and we were happy. Then I got the bad news. They just said, oh, I’m sorry, but we are switching to another agency. I had to get a new worker and some of them were good and some not. Some of them pay more attention to him. Some of them, are talking on the phone and he’s screaming. Some of them, as I said, know how to talk to him, distract him. Some of them, ignore him when he’s agitated.
>
> Whenever you call this agency, they put you on hold. You know after you listen to all their music they ask you, if you want to reverse the number, we will call you back. It’s like a circle unnecessarily because we lose so much time. There is no direct phone number to a

> supervisor as before, which is very inconvenient and very frustrating. Then most of them, they're not nice.

Rachel has numerous PSWs working with her husband. "I think one PSW probably has more skill then the other. I think she has more care and compassion and sees him as a man as a whole. For the other one, it's more like a job."

Two participants in this study live just outside of the GTA. Due to the smaller region and more personalized rapport with case managers, these individuals are happier with the service. "I have to say; our case manager has been phenomenal. When we left the hospital in one city and went to another, she made sure that nursing services would be there" (Jill). George provides an excellent description of his experience:

> My wife was septic and in the hospital for two months. Two weeks prior to coming out, arrangements were made for her to get all the care. We were told we would be getting 21 hours a week. When we initially came home, the services were there that day, but going forward it was a struggle to get anything consistent. The agency that was allocated seemed to have a real problem getting prepared. Despite the fact that they had two weeks' notice, they hadn't put a proper allocation of resources in place. They were canceling. They weren't coming on time. Sometimes they called, or just didn't show up. Then they would offer additional hours to make up for the time but at different times of day, which were not required or didn't make any sense.
>
> Eventually it just got worse and worse. I had meetings here with my case manager and the manager of the agency. It got very brutal because I was quite honest and straight forward, telling them all the problems. I would call when there were missed visits. Any kind of issues I would call to talk to the supervisors. I left messages, they never responded, never called back. They always seemed to be short of resources on the weekends, on holidays and all those kinds of things.
> It got so bad that finally, the case manager moved us to another agency. It was a bureaucratic nightmare. The second agency has never come close to canceling. There's a better line of communication. They'll call, say we're having problems getting somebody. It's obvious to me between the two agencies, that the PSWs are happier at their job.
> I don't hear the whining, complaining. The other ones used to whine and complain to me about their company and the conditions upon which they work.

The second participant, Jill, also from outside of the GTA, likewise switched agencies. She states:

> There were issues with some of the nurses they sent out, so I asked them not to come. They weren't capable. Then as far as the PSWs, some of them did a bit of work and some did nothing. One girl would walk him up the street and back and then she was gone, hello here exercises? If I wasn't staying on top of it, it wasn't getting done. I would call the manager, to request a meeting, he didn't show. I finally said no more of this agency, this is just ridiculous.
>
> PSWs from the second agency, what a difference. How can agencies be so different? These girls are on time, they're professional, they work from the minute they get in the house to the minute they leave, it's just unbelievable. I know that this second place pays a bit more. They seem happy, the PSW's.

In the GTA, none of the caregivers mentioned being offered an opportunity to switch agencies. However, there is one agency which provides home care services to holocaust survivors. Individuals receiving care from them, have had positive experiences. They receive the maximum number of hours, consistency in care workers and a match to language. Caregivers can also call to request more hours if they are going on vacation. Maria simply has to call the case manager and say "I'm going on vacation. I need two extra hours per day for three weeks and they give them to me." The PSWs who come in from this agency are also willing to complete more tasks such as cooking, and cleaning.

Theme 4. Summary and interpretation

Experiences with case managers, agencies and workers vary. Case managers are given the task of delegating care to clients. Some managers demonstrate more compassion then others and have a better line of communication with IFC. Since there is no regulation that oversees the quality of customer service, not all caregivers are fortunate to be assigned to a kind and dedicated case manager, that will respond to their questions and concerns. In addition, in the home care sector, formal care work is often precarious. Agencies are not required to provide standardized pay or guarantee of hours to their service providers, in turn, impacting employee satisfaction. Nurses/PSWs that are happier with their working conditions (i.e., better pay), are likely more committed to client care, which is noticeable by IFC. Furthermore, only regulated health care professionals (nurses) are accountable to their governing colleges for safe handling of clients. PSW's are unregulated and caregivers aren't able to make a formal complaint to a regulatory body regarding misconduct. A concern can be voiced to the agency regarding the worker, but there is no guarantee of replacement.

Theme 5. Challenges with receiving hours, and consistency in care

Caregivers of clients with minimal needs, report that the hours they receive are for the most part sufficient. However, they are also worried about the future, should care needs change. "I am concerned, and my concern is that they will drop the number of hours. I'm happy with what we're getting since the hospital and it's three hours a day. There will be a re-assessment soon" (Dina).

For the most part, caregivers, even if eventually satisfied with the number of hours received have had to fight to receive them (as in George's and Jill's previous descriptions). In addition, services are consistently being re-evaluated, and some have had their hours reduced not because of the client's improved health, but due to budget restraints (as per Lily's previous description). Since funding varies between LHINs, some may be more generous with hours. Linda moved from one CCAC region to another, in which she receives more hours (from three times per week to every day).

In the previous section, it was found that consistency in workers is in part agency dependent. It is also dependent on the caregiver's self-advocacy and persistent requests for regular care. Changes in service providers is very stressful to both the IFC and client. For caregivers, they need to make sure that the worker is competent and is trustworthy in order to leave them one of one with the client. For clients, especially those with dementia or anxiety, constant changes in workers are very confusing and create additional emotional disturbance. Allowing strangers into the home is a challenging experience for many, especially for the vulnerable. As such, having the opportunity to establish rapport with a service provider is crucial.

> My son's anxiety is very severe, so he's not good with new people. He doesn't want them. I ask, please send me people who were here before. So much fighting because they are too lazy to look at the previous schedule. It's easier to just send someone else. (Emma)

> I have the same people during the week. On the weekend, I never know who I'm going to get. I don't normally leave him with them. I'm usually always here when they come. (Debra)

Interestingly, one of the reasons why some caregivers refuse more hours, is because they do not wish to have unknown service providers.

> I get two hours per week. I think I would be happier if we did have more hours, but the only problem is I don't want a different person here every day. We are used to one lady and she is like an angel. And my mother's nervous, you know, she doesn't like strangers. (Dina)

Consistent care also refers to uninterrupted care. Many caregivers report last minute cancellations, and changes in appointment times which is very disruptive to daily routines (work, childcare). George describes his experience as follows:

> They were cancelling. They weren't coming on time. Sometimes they called, or just didn't show up. Then they would offer additional hours to make up for the time but at different times of day, which were not required or didn't make any sense.

Linda describes the following:

> Last Sunday morning, the PSW, was supposed to come in at eight. I got a call at nine o'clock that no one was coming. So now, the kids couldn't go to hockey because I had to take over and it changed the entire day. Everyone's affected.

Nelli, a single of mother of three and full-time caregiver of a child with a disability, receives care from 9am to 5pm for her daughter while she is at work.

> When I found out they weren't coming, there was always an excuse, so that became a little stressful for me. I was told to have a backup plan. I'm like, I don't have a backup plan. There's no one else to do it.

Nelli, had to go to work to support her family. In this situation, the child’s hospital got involved and vouched on behalf of the patient.

Theme 5. Summary and Interpretation

The number of hours allocated for home care services depends on the budget of a particular CCAC/LHIN, which is arbitrary and may change on a monthly basis (Grant & Church, 2015). Some CCACs/LHINs are more generously funded, and clients residing within the region may receive more publicly funded care. In addition, there is no uniformity among CCACs/LHINs on the criteria to determine eligibility for care. The Resident Assessment Instrument-Home care tool used to evaluate the number of hours an individual should receive, is inconsistently scored. The experiences of IFC speak to these discrepancies who often end up fighting for hours. In addition, hours may be issued and then revoked regardless of the client’s condition.

Obtaining consistency in services is also challenging. Cancellations, changes in appointment times and inconsistent health care providers coming to the home, are common phenomenon in the public home care sector. Such happenings are the result of poor customer service in agencies and high job turnover. Agencies which have contracts with the LHIN do not have to report on quality standards or client satisfaction. With little incentive to improve on client relations and greater emphasis on profit generation, the quality of service suffers. In addition, the precarious nature of work within the home care sector, often comes with a difficulty in retaining staff that delivers care on a continuous basis to clients.

Theme 6. Poor matching of needs, limited tasks, and poor training

Clients’ needs vary. Some require an adjustment of service hours while others require a service worker to be of a particular gender or speak a certain language. In Mia’s case the

PSW comes in 3x/week for 1.5h to provide her mother with a shower. According to Mia, “what if you wanted to have a shower every day? Split up the five hours and make it five days a week, one hour each day, but this arrangement is not offered.”

In Rachel husband’s situation:

> Matthew is six foot five and it’s not like he’s gone completely. So, you know, he is still conscious and still shy. If a woman came to take him to go to the bathroom, I want to respect Matthew for that. From the beginning with the care coordinator, we wrote down, it has to be a male. I think at least twice now I’ve had to deal with the agency to say male or don’t bother sending.

Lily needed a strong PSW that could lift her husband for transfers. “We had one women come in, she was not strong. She could not move my husband. I was afraid that he would fall.”

Other clients only speak certain languages, which poses a challenge for obtaining care. Caregivers report that agencies sometimes employ service providers who speak a given language, but they do not always accommodate the need. In Lily’s case, it took some time to get a Russian speaking PSW coming in consistently. The client simply refuses all other workers.

> We had a lot of different PSWs. Finally, Anthony came and he is okay, he’s a nice guy, very professional, very responsible with what is he doing. It’s really good because he is Russian speaking and my husband likes him. It took about two years to get him. (Lily)

In addition, some caregivers have report that it would be helpful if PSWs could engage in more household tasks (related to the care of the client), such as tidying up after they are done, or washing the dishes when the client finishes eating.

> It would be nice to know that maybe the PSW could help with some household things. For the one and a half hours, she has a little bit of time to, you know, fix my mom’s bed and that type of thing. More duties because they don’t really do things like, tidy up and, they don’t particularly engage in anything else other than the direct care. (Mia)

Finally, caregivers report that there needs to be more training for service workers in areas of dementia and diabetes. With dementia, a certain amount of understanding and patience is required. Rachel tends to tell the PSW what to do during the session so that her husband does not get agitated.

> I say to the PSW, here's the list. I just need you to heat up the food. I need you to sit with him, let him have his food. You guys play games. I'll deal with the shower because I know how strict I need to be. The PSW, is still learning how to be with him. Maybe strict isn't the right word but you know, there's steps.

With a diabetic condition knowing when and how to correct sugar levels is important. "The nurse, for instance, can give her a snack or something like that, so maybe more training on diabetes. That does come with experience, making the decisions on that" (Nelli).

Theme 6. Summary and interpretation

Care isn't just about sending a worker to a client's home. There needs to be some flexibility in the services that will accommodate the needs of the IFC and client. Hours are often stringent and unaccommodating, posing an extra challenge to caregivers who must re-work their schedules around home care services. Care is also hindered by a mismatch in language and gender. In order for caregivers to have the opportunity for respite, rapport needs to be established with the service provider which includes trust in their competency. Often times, the caregiver has to direct the worker to the needs of the client or end up providing the care themselves.

In the home care sector, providing clients with flexibility is often not feasible. Since the majority of workers are female, it is challenging to accommodate gender requests. In addition, health care professionals are responsible for training in their respective field. This training comes from formal education that provides them with credentials to practice.

Professionals also have expertise in different areas of health. However, high job turnover and difficulty in staffing in agencies, is not conducive to accommodating individual needs (flexible hours, diagnosis/training match). In other words, caregivers rarely have the opportunity to choose a provider or must wait for a long time for a personal match to become available.

Theme 7. Personal challenges of Informal Family Caregivers

Personal challenges of IFC refer to their physical, psychological and financial needs. Most individuals report feelings of exhaustion and stress related to their caregiving role. They also describe limited social engagement with others, feeling guilty about not being able to participate in family activities and an overall sense of a loss of identity. On the financial side, some individuals report that they would like to hire additional care hours privately, but their resources are limited. Finally, with the exception of one caregiver, none report respite when public home care services are initiated. For the sake of clear organization, the following table includes excerpts from the voices of caregivers.

Participant	**Personal Challenge**
Rachel	I think my biggest challenge is just taking care of myself and I think, grieving the loss. I just can't go somewhere without always having him on the back of my mind. The grief is in my face day to day. That's my big thing. That's my journey. There's a grief because a person dies. This is like daily losing and it's in your face. That part I don't think too many people get.

	There's this general impression, that if you've got an hour, you can go for a coffee. You know, it takes me 10 minutes to get out of my street onto the main street and then where am I going to go for coffee? If it's more hours, then I can say to a girlfriend, hey, I do have an hour.
Debra	I want a more normal life and getting out, socializing a bit because I realize that if you don't, you're going to start resenting the person and that will cause issues. I'm trying to do it and my husband is very much encouraging me to see my friends. If I've got to hire somebody, I can do it for maybe two or three hours. I mean we're talking, $40-60 a day, that's a top amount. That may be an issue.
George	My identity, I've lost my identity. I can feel comfortable perhaps just leaving her for an hour or so if she's in bed in the afternoon, sleeping or whatever. But that's about the extent. Most of my activities are limited to looking after her. What can you do within a short period of time? You know, socially, it isn't much.

Samantha	I will have a grandchild come March 18th. I may be asked to babysit and I'm already thinking about how am I going to manage. I have depression that's related and I do not sleep. I do feel guilty, as I say, regretful that I haven't been able to really be a part of my kid's life through university. I guess sometimes you feel like you're just flying by the seat of your pants the best you can. I probably need more time for myself. I've always been that kind of person. I have trouble looking after myself.
Emma	I don't have many friends because I don't have time for them. I don't have a life. I'm very drained, so I'm taking some supplements. My husband has worked all these years and he doesn't make much money as a custodian. We can't afford private services.
Mia	You constantly have to be alert, worry about someone. Extra services are not financially feasible. I haven't gone on vacation for a while.
Jill	Let's say two hours of care in a row, would give more respite.

Theme 7. Summary and interpretation

Informal caregiving is a daunting journey. The underfunded and understaffed public home care sector does not provide sufficient supports for caregivers. The experiences of participants portray limited opportunities for respite, and psychological distress. The majority of participants are not able to maintain employment (also demonstrated quantitatively) due to their caregiving roles. Subsequently, they are not able to afford to hire home care services for private pay and do not have time for respite and/or engagement in paid labour- a cyclical pattern.

Privately Financed Home Care- Qualitative Findings

Participant Narratives

This section presents the individual stories of caregivers receiving privately financed services. To protect identity and at the same time give a sense of the persons in the experiences, fictitious names are assigned to the participants. Two caregivers are randomly chosen for full narrative presentation.

Holly

For eight years, Holly was a caregiver. Her mother was in an accident which severed her optic nerve and left her legally blind. Her health spiraled downwards over the years. Although Holly did not reside with her mother, she was still accountable for the organization her care. Her mother refused to be assessed for public home care, and CCAC does not enter the home if the client disagrees. As such, Holly had to hire services from a private agency. The first agency they chose, was very poorly run, but the second agency is excellent.

> For three or four years, we were trying to work with the first agency and we finally gave up. In 2015, we hired the second agency, talk about awesome care. The Cadillac of service, I can’t say enough about those guys. In February of 2016, all of a sudden my mom took a real downward spiral and we’ll never know if it was a stroke or the leukemia was just really

> starting to take hold. But, my mother didn't want to be hospitalized and so from, February of 2016 until her death in April of 2018 we had round-the-clock care for her. I liquidated my mother's investment portfolio just taking care of her. I'll tell you, if you have 24-hour care, in one month you're looking at $18,000. It was good, we had no cancellation. We had a good experience with private. They loved my mother, and everybody wanted to be on that roster to come and help her.

On the personal side, since Holly lived far away from her mother, she found it stressful knowing that she cannot be there. It was also challenging organizing/making sure that there were enough finances to pay for all the services. "I think the other thing is the social stigma and I know many people would not have taken care of their parents like that. You wind up getting marginalized."

Rose

Rose's parents lived in an independent living home. Her father developed dementia and also had a minor stroke at which point Rose (primarily) and her mother became caregivers. In the mornings, prior to work, Rose went to care for her father. After work, she picked up groceries and whatever else was needed and once again returned to her care duties. Initially, CCAC was providing services. A PSW came in for one and a half hours each day. However, this was not enough as Rose's mother could not handle the father's care. There were also issues with consistency, scheduling and expertise.

> CCAC just didn't have PSWs available at the time that we needed and they didn't have as much time as we needed. My mom was totally burning out. When I saw her not being able to remember some words, I realized I had to do something or she was going to be in the nursing home, before my dad. CCAC were coming in at 6:30 in the morning, it was waking my mom up. We really needed help later, like 8:30am and CCAC couldn't do that. The CCAC also prepared meals they could do, like heat in the microwave but they wouldn't do the actual food and my mom wasn't able to anymore.
>
> Also because of the frontal lobe dementia, my dad got a little bit inappropriate, especially when he had a shower, so the CCAC girls refused to do it. They said they weren't comfortable. I took over the shower, which to be honest, was really difficult for me,

> especially at first. I got used to it, but then it was probably really hard for my dad too. That became a big issue and was so upsetting to my mom. So, we decided we wanted to hire our own PSW, and we'd have the same person come every time and you know, build a relationship. We could explain the dementia. I don't know why those CCAC girls couldn't handle that when they should.

Rose initially wanted to hire care from a private agency, but they were only willing to send a PSW for a minimum of three hours at a time, which was not convenient. Luckily, Rose's friend, a nurse, was looking for work, lived nearby and was able to come in for an hour and a half as needed. Rose also hired another friend, a PSW, who recently quit her job at a nursing home due to poor working conditions. Cost was also more reasonable, and they had experience working with individuals with dementia.

> We were paying $25 an hour for one and the other we paid $20 an hour. The agencies, I think were $27 an hour or something and they wanted the three-hour block, so that was too much. The girls we hired could do anything and were willing to do anything and I knew that it was always the same people. When we had CCAC, I never knew who would come and that's really stressful for my mom having different people. They didn't always know what to do so she was explaining it every time.

On a personal level Rose describes her overall experience as follows:

> I actually gave up a lot of work income, a lot of work hours. In fact, I had to take a certain kind of employment that was very flexible. So now I have my own tutoring business. Private was so good for me because I took two morning shifts and when we hired, they did all the rest. It was such a relief because I actually had breaks, you know, I had days that I didn't even go over. So yeah, I would say a huge help for me. My mom, was so much more comfortable with these two women because they were always the same people and she built a bit of a friendship with them.

Consistent Themes

The following seven subsections present the consistent themes described by participants pertaining to their experiences with privately financed home care services in and around the GTA. The themes are supported by the participant's own words from the interview transcripts in order to best describe the experience.

Theme 1. Caregiving is a routine or managerial role

In this group the majority of the participants do not reside with the clients. Those who do, report caregiving as a structured routine. This routine is needed in order to ensure that the needs of the client are met and that the caregiver is able to plan their daily lives. Fred's week is fairly consistent as he cares for his wife:

> On a typical week, I get up early, early enough in the morning between five thirty and six, and have a latte. Then I read the newspaper or shower and get things ready for her. Such as the medication and her breakfast. When the PSW comes in anywhere between seven thirty and eight we're ready to go. Throughout the day, I try to do some range of motion with her. I try to spend time with her.

Linda is a single mother of two, who works full time and is a caregiver for her mother.

> I tend to do my mother first thing in the morning because she can't help herself. Once I feel like I've gotten her out of the way than I tend to deal with the kids, in that order. It begins with my mother's breakfast, making sure she has the pills, making sure that the meal is prepped and left in the microwave, so the PSW can access it and pass it to her as she needs it. Then it's getting the children's their breakfast. My son has moderate ADHD so it makes it a little tricky to get him to stay on course. Those constant reminders, reminders to get him to remember what he went to do to get him to stay on task. Then the little one is just five, so he's doing his own thing. In the morning, it's a bit of chaos. The whole goal is just trying to get out the door so I can go to work.

Caregivers that do not reside with the client describe their experience as always having to manage the care and the services that are received. "It is like running a business myself" (Danna). Regardless of the residence, all caregivers report having to ensure the well-being of the client. "The majority of your week is spent, you know, trying to coordinate these appointments and going to these appointments" (Mark). Vicky makes sure to check-in with her father at least a few times a day.

> PSW is coming in at eleven o'clock, so I usually call him, at eleven o'clock in the morning and then I'll call him again at four o'clock in the afternoon. Just to let him know that I'm here, if I don't get up to see him.

Clients who receive 24h/care and do not reside with the caregiver, still require the caregiver to coordinate their services. "It's making sure that the service providers show up when they promise to show up" (Eleanor).

Theme 1. Summary and interpretation

The daily involvement of an IFC paying for private home care services depends on their living arrangement. Individuals who reside with the client routinely engage in care tasks. Those who reside separately (the majority in this study), take on a more managerial role of coordinating services and making sure that the client's needs are being met. Regardless of the living arrangement the caregiver is continuously involved in supporting the client and ensuring their wellbeing.

Theme 2. Finding out about private services

Caregivers report many interesting methods of finding private care including word-of-mouth, brochures, personal advertising, social media groups, and online directories.

According to Mark "People really do need to shop around in terms of this private stuff because it's not the same. These agencies provide very different services." Mark also notes that the agency he first called did not provide services in his catchment area. He did a lot of research and ended up purchasing services from a large agency that serviced his area.

> I noticed that there were a lot of smaller home care agencies out there. I'm getting a feeling that there's a lot of *live by night* organizations as well that are out there. I could tell when I would look at the brochures. Some of them were riddled with spelling mistakes. There was also nothing about accreditation Canada standard or something. Sometimes I would look for that as well and wouldn't find.

Eleanor conducted her research on the internet.

> There was the googling and the research and looking at the complaints and using my own professional network. Here's the criteria we're looking for: How are they respected in the community? What are people saying? And so, then there is price.

Similarly, Darla interviewed many PSW's: "I did interviews with different people and I think it was somebody that connected with us." Danna describes her experience as follows:

> I went through the internet and since I'm an occupational therapist, I contacted agencies that I knew and worked with in the past. I also looked for agencies that had more experience with dementia. Some of the agencies never even phoned back. A lot of them didn't have enough staff.

Frank interviewed many independent PSW's prior to hiring. He advertised in the newspaper, and then relied on word-of-mouth and Facebook. Similarly, Vicky also received a suggestion regarding services. "It's kind of an ironic thing because my dad was having trouble living on his own in this home. One of my friends said, well, have you ever heard of X agency?" (Vicky).

Sharon was very careful with her selection:

> I went to a private agency but I was also very much part of this interview process and basically my first thing was interviewing them and telling them, you know, you're working for a great family, but you have to remember something: This is a very serious job. The worker can't be on her cell phone. She always has to be paying attention to my mother and paying attention to her every need and I will make sure to treat her very, very well. Some of them were outrageous. Lack of transparency where, you know, just no histories of the particular workers.

Theme 2. Summary and interpretation

Purchasing care out-of-pocket gives IFC the ability to make a choice of who to hire based on their needs. However, there is no one particular place where IFC can look up a private agency or independent service provider. It may take time to find (using various methods) and employ the desired services. In addition, since there is no formal regulatory oversight to ensure credibility of agencies/providers, caregivers must carefully interview prior to making a hire (refer to Considerations for Private Care in chapter 3).

Theme 3: Initial reasons for seeking private home care services

Caregivers report numerous reasons for choosing to pay for private home care. These include client being ineligible for public care, inconsistency of public care, the need for additional care hours, and simply choosing to forego the complexities of the public system altogether. The following table depicts the voices of caregivers with regards to this theme.

Danna	I think when he was first referred to CCAC, he was pretty independent, but needed a lot of supervision. He was physically very mobile, but needed like a sitter because he would get lost and will want to leave the house a lot. That didn't really meet the criteria for public care. It was easier to hire somebody privately.
Sharon	As the disease progressed, I found that a lot of public health was very unreliable. They would send different people who really were not trained adequately. Some of them were rough. And again, I was on everything. I know what gentle care is and I know what being stern is and just doing your job. Some of them I was just not happy with and I was always on the phone with the public system, trying to have one continuous person.
Vicky	It's a real hit and miss with them the public system. I never knew if they were in or not. So, I said forget it. It was just too inconsistent. I didn't have the trust.

Mark	I think part of it was the fact that we were finding that we were not getting as much support from the public. When my mom first started, they were a little bit more generous and they were giving four hours a week. Right now, it's two hours a week.
Holly	My mother kept saying no to an assessment. We never even brought a CCAC into the house because they will not come if the person in question refuses. It was simpler to hire private care.

Theme 3. Summary and interpretation

Those who seek to pay for private home care services do so for numerous reasons. However, it is evident from the voices of IFC that the publicly funded home care system does not provide enough supports to accommodate their needs and the needs of the client. Thus, either supplementing or forgoing publicly funded care is chosen.

Theme 4: Care is agency and service provider dependent

Private agencies and service providers vary. As Mark notes in his previous description, some of the agencies seem like they are *live by night* organizations. As such, participants need to be careful when choosing where to hire services. It often takes a few tries before an agency or independent provider is selected. Danna describes her experience as follows:

> One agency sent two women that weren’t physically able to keep up with my dad. They weren’t good, it wasn’t a good match with his personality. They wanted to engage more with my mother than my father and so then, it was finding the right agency. One agency had a real problem with consistency. I felt that I needed to be there every time a new person started in order to give them an orientation. I mean they were changing the staff members too often. I didn’t feel that the agency really cared. We switched to another agency, which was better.

Vicky describes the following experience:

> They were just short on staff, and I said, I don't care what you do or where you go, but you have to find somebody. I think they finally realized that there was a real problem and they went and got their providers from another company. Those people were horrible, some of them. I don't think that they should be putting a new PSW directly into a situation dealing with dementia because, I don't think they really comprehend what's involved and how challenging and stressful it can be. My weekend PSW, lost a client. That meant she had availability. So, then I said, okay, you know what, shift everybody around and do what you have to do but I'd like her to be there five days of seven. That's what they did.

On the other hand, Holly had a great experience with the first agency she called. "We hired C*and that was the owner who put me in touch with you. Talk about awesome care. Oh my God. The Cadillac of service or I mean, just like, I can't say enough about those guys."

Amanda had to go through a number of independent PSW's before finding the right fit for her mother. "Sometimes some of them, they were saying no, that's too difficult to do. That's too hard or your mom is not behaving. She's not sleeping all night, sometimes screaming or getting in accidents."

For Darla, it was also difficult to find a good PSW for her son.

> You go through people who don't show up. They don't quit, but they never show up for work. You hire them, they work a week, they're gone. You never hear from them again, or you hire people and they keep calling in sick because they don't want to deal with the situation.

Theme 4. Summary and interpretation

Privately financed home care agencies vary in the quality of service they provide. Some agencies have excellent customer service and can accommodate client needs, while others are not able to stay in business. As such, IFC must carefully search (using methods previously discussed) and choose an agency that will match their particular needs. For example, some agencies may be more focused on servicing clients with dementia or have male workers on staff. In addition, it is important to validate an independent health care provider's (not employed by an agency) credentials in order to prevent fraudulent service. To-date, there is no formal regulatory body which oversees the privately financed home care system. As such, this sector comes with inherent risks. Since client are usually vulnerable individuals, it is essential that IFC make an informed decision regarding the hire of an agency/independent provider.

Theme 5: Consistency, completion of extra tasks, matching of needs, no contracts

As previously mentioned, caregivers are able to shop around for an agency or independent service provider. Once an agency or independent service provider is chosen, caregivers report benefiting from limited cancellations and consistency in services. According to Linda:

> You see the diligence. If she's not able to make it, they're so quick to make sure she's replaced and that you're notified compared to the public. When it's private, you're going to be notified if she's going to be late. If it's a different person, you're going to be asked. Would you like me to send someone else?

Darla, as well as others have worked with the same service provider for many years. In her case, the PSW had been with her son for over eight years. "We decided we wanted to hire our own PSW, and we'd have the same person come every time and you know, build a relationship" (Rose). According to Vicky:

> The public system I just don't feel comfortable with them. They are hit and miss. Like I said, they came in sometimes and sometimes they didn't, I never knew. I couldn't get any answers. So I just said forget it. It was just too inconsistent. The PSW have now has been with my dad for over five years and she is the most faithful, reliable person ever.

Fred insists on consistency:

> If I think that the person is there simply to get the job done in two and a half seconds and get out of the door so they can go home early or they can go for a coffee break in between the next client, I let the agency know.

In addition, caregivers report that in the private system, the service provider is willing to complete extra tasks around the house. According to Mark, “the main difference I found is the fact that they will do a little bit more than what’s done on the public side. This includes light meal prep, washing dishes, tidying up and changing a light bulb.” Linda describes the following:

> I find when it’s the public, there’s a limit and it’s dictated. She might be able to wash a dish, but it has to be a two-person transfer. When it’s private all of a sudden, she can just do a one-person transfer, the same company. They don’t care, she breaks her back or you rake her back. It was private. You tell them what you would like her to do, they will bend. The line becomes blurry.

According to Eleanor:

> You know you’re paying for one hour, they’re coming for one hour. If he needed to get clean, he showered and got dressed. If he left socks on the floor, they would have picked up the socks and put them in the laundry bag.

Fred was looking for a provider that was an appropriate personality match.

> It comes down to a personality situation. You’ve got to be able to live with that other person as well as talk to them. A lot of the people that think they can do private or in home are not compatible with somebody that’s still basically home bound. Like myself, who retired. A lot of these people, are used to the family members leaving and, they’re there for the day.

Darla too, searched for a provider that would be a good fit for her severely autistic son.

“Through interviews, figuring out who will connect with my son. Who understands, and is aware that he can get violent”.

Privately financed agencies themselves provide assessments with families in order to best match with a provider. They conduct “A comprehensive in-home assessment that’s complimentary to help you figure out what your needs are” (Mark). “I did not want anyone that smoked, someone very clean, someone very conscientious and someone to treat my mother like it’s their mother” (Sharon).

Clients can also dismiss service providers who they do not favor and request for someone else instead. "You get a little bit of a choice. If my mother didn't like the person, she could say, I would like somebody else" (Mark). In addition, clients can request a service provider of a particular gender. According to Danna:

> It wasn't until this one agency that I contacted that did an assessment to try to match my dad with the appropriate care, the appropriate character that works.
> It was actually, a boy, a young man. My dad bonded with him man to man and felt quite comfortable playing catch and playing ping pong and doing stuff around the house with him, whereas he didn't feel as comfortable with women.

For Amanda, the match was about finding someone that speaks her mother's native language (Polish) and is able to cook culturally appropriate food.

Finally, caregivers are not bound by a commitment to agencies or providers. They can cancel, change and stop services at any time. They can also call for urgent services as was the case with Betty when she needed an overnight provider to look after her mother while in hospital. According to Danna:

> One thing with these agencies is that there's no contract, it's just week by week. You are not tied. You can tell them you don't want them to come. It could be Wednesday and you could tell them you don't want them to come anymore on Friday and that's the end of it. They don't call you.

Theme 5. Summary and interpretation

Privately financed home care agencies run a business. They require consumers to sustain their existence. In order to keep their clients (caregivers) satisfied, every attempt is made to best accommodate care needs and preferences. Caregivers can request a service provider of a particular gender and change providers until a personality match is found. Cancellations are rare and replacements are offered in a timely manner should they occur. Service providers are also willing to complete extra tasks around the household that go beyond the duties of care.

The ability to choose a health professional is key to establishing rapport and trust. Once a consistent dependable provider is selected, caregivers can have opportunities for respite or other endeavors such as paid labour to mitigate financial struggles. As presented quantitatively, most IFC utilizing privately financed home care are employed and able to live separately from the client while contracting the services.

Theme 6: Challenges with private care

Other than the already discussed challenge of finding the right agency or independent service provider, caregivers report a few others including: the inconvenience of time block purchase, their own financing capabilities, their schedules, and poor staffing in agencies.

Private agencies typically require individuals to purchase care in few hour blocks (anywhere from 3-4h), simply because it is not lucrative to offer services for shorter periods. For some clients, this is either expensive, or they do not require care for long duration. “The agencies, I think were $27 an hour or something and they wanted the three-hour block, so that was too much” (Rose). Betty lives in a small condo with her mother (the client). Ideally, she requires private supplementary services a few times a week, twice a day, for an hour each time. However, the agency will only accommodate three-hour blocks.

> I understand that it doesn’t make sense for agencies to send a worker for just one hour, they don’t make money this way. However, my mother does not need them there longer. She needs a shower a few times a week and some other small tasks that don’t take much time. I don’t want strangers to be in my personal space. You know, it’s stressful to have an extra individual in the home, especially since mine is a condo. It’s not because we can’t afford it, it’s because it’s intrusive. (Betty)

There are also price differentials for private hours between a weekday, weekend and holidays. Mark describes his experience as follows:

> There was a price differential in terms of regular week, versus weekend versus say statutory holidays. I don’t remember what the minimum was, but it was two or three hour blocks that we had to purchase. You have to have that block of time so it just starts to become

> prohibitive. When we scheduled, the public workers versus private, plus our other regular appointments, it became almost a bit of musical chairs trying to move things around. Cost is becoming a bit of a factor; the price is outrageous. On statutory holidays, you pay a higher fee.

Interestingly, Mark obtains his private services from the same agency where he receives publicly funded care, as this agency also has a contract with the LHINs. He is the only participant with such a scenario and feels that the agency is always trying to push/promote their private services.

Private agencies too, have challenges finding good service providers for hire, making staffing an issue. Vicky waited until one of her excellent PSW's lost a client, so that she could obtain more hours.

> I had two really good PSWs, and one had been with my dad like six years and she ended up moving. I had to get another one and I got the other one that was doing the part time with her. She came on and then she also moved. It was more like they would work and then they would go somewhere else. The bad part was, that C* didn't have anybody for replacement. That was like really difficult for me because that meant that I was like his full-time caregiver. They were short of staff; they didn't have anyone in my area. I said, I don't care what you do or where you go, but you have to find somebody. I think they finally realized that there was a real problem and they went and got their providers from another company.

According to Fred: "agencies also have trouble finding PSWs. It's almost like there's no organization in terms of where these PSWs can go to put themselves out there, that they're qualified and looking for work."

Theme 6. Summary and interpretation

Hiring home care services privately requires both finances and scheduling flexibility. For profit reasons, agencies will only deliver services in blocks of time. For some, it is expensive and for others it is not needed. IFC who wish and can afford to have services for prolonged periods of time can certainly do so. Meanwhile, they can work or obtain respite. This is especially the case for those who do not reside with the client (the majority in this group). For those who do live together, respite may be challenging because having providers (especially new ones, where no rapport has been built) in the home is intrusive and overwhelming. Staffing is also an issue, due to the high job turnover in the sector. Thus, IFC may have to provide care themselves while waiting for service.

Theme 7: Personal challenges and opportunities of caregivers

Personal challenges of caregivers refer to their physical, psychological and financial needs. The following table includes excerpts from the voices of caregivers.

Participant	**Personal Challenges**
Eleanor	Caregiving is very tiring. It's physically tiring. It is mentally tiring because you're not only doing your own stuff; you're doing somebody else's. You know, the emotional support. Anybody who is not working and this is their full task, I don't know how they do it. People look at me and they don't know how I can work full time. I go to work for a break.
Linda	You can never sleep in. You can never be sick. You can never be depressed. You can never just be down.
Amanda	I'm giving up a lot of vacation days. In 2017, the provider allowed me to go for 10 days. Mom's just scared of me leaving.
Fred	As a caregiver for someone with dementia or somebody with Parkinson's or some other situation

	that’s to do with mental, you become labelled, you become socially rejected. Luckily if you can afford private care, you are able to get out of the house. You are able to kind of maintain your own physical needs and your own mental sanity.
Holly	When your parent gets into that part of their end of life, it's astounding how insensitive people are. People on the periphery, who didn't know me, didn't understand how my mother would have that much money to do all that.
Vicky	I try to go at least once to twice a week and check on him and make sure he's okay. Check in with the PSWs. They're really good. It gives me peace of mind.
Sharon	The workers were living with my parents. So, you know, I guess we were very fortunate that we had the money to do that.

Theme 7. Summary and interpretation

Individuals who reside with the client or spent a significant amount of time on care tasks, report feelings of distress related to their caregiving role. They also report limited social engagement with others. Those IFC who do not reside with the client and are primarily responsible for coordinating services, still find it to be a stressful journey because the wellbeing of the client is always on their mind. In addition, individuals find that once they are in the role of an IFC, they are automatically stigmatized by others. On the financial side, those receiving many private care hours, have the monetary resources and wish to do so. As such, these caregivers are able to reside separately, maintain employment, have additional help, and/or obtain respite, knowing that the client is cared for.

Research Questions: Summary of Themes, Interpretation and Comparisons

On the whole, this research has illuminated the experiences of IFC in the context of neoliberal reforms which have created a decentralized and underfunded public home care system, encouraging individuals to turn to the private marketplace. The experiences of IFC who seek home care services from the public system and/or have the opportunity to hire supports privately, are illuminated in the research questions presented in this study and will now be answered (see methods section). For the sake of clarity, the summary of main themes and interpretation of findings that follows is separated by public and private groups and comparisons are made where applicable. Public refers to those participants receiving services from the publicly funded home care system, while private, refers to those receiving services purchased out-of-pocket. The voices of those supplementing public with private care are reflected in their respective group. Those questions asked only of the private group will be indicated. Further discussion of implications will be provided in the next chapter.

1. What does a caregiver's typical day look like?

Public- Participants describe caregiving as constant routine. With the exception of one individual all are living with the client. This living arrangement has shown to be indicative of a life immersed in care work. All participants report engaging in direct and indirect care tasks including personal care, food preparation, medical care, mobility assistance and transportation.

Private- Four of the twelve participants who are living with the client, report caregiving as a routine, similar to the public group. The other eight caregivers took on more of a managerial role in the care of the client, consisting of arranging/coordinating the services, keeping track of finances and visiting as needed. As opposed to the caregivers in the public group, this living arrangement means that there is less engagement in the routine of personal care, food preparation, medical care, mobility assistance and transportation.

2. What are the reasons caregivers decide to seek home care services?

Public- The need for home care services arises from the difficulty and lack of knowledge regarding the proper care of an individual. Caregivers often find themselves struggling with physical and emotional burnout as a result of the constant provision of care tasks for the elderly, or persons with disabilities. Lack of sleep, pain, limited supports, and financial losses are detrimental to health and well-being. In addition, clients are often discharged from hospital with conditions requiring medical attention that is beyond the scope of the caregivers' knowledge. Taken together, the receipt of formal home care services becomes an avenue through which caregivers can obtain some assistance and support for their roles.

Private- There are numerous reasons in addition to the ones listed above, for why caregivers choose to seek private home care services and are willing to pay out-of-pocket. These include: being ineligible for public care, inconsistency/scheduling challenges with public care, the need for additional care hours, and simply choosing to forego the complexities of the public system altogether.

3. Do caregivers purchasing privately funded services use them to supplement those that are publicly available?

Private- Half of the participants in the private group are supplementing the public services. The primary reason for this is that not enough hours are being received from their LHIN (or CCAC at the time) or that the services are not being provided at a time of day that is convenient or required. Caregivers also pointed out that case managers who felt that clients can afford private care, are more stringent with the allocation of services. Thus, further contributing to the evidence of the subjective nature of the home care system as a whole.

4. How do caregivers choose a particular private home care agency/independent service provider?

Private- Caregivers report a variety of methods of finding private care including: word-of-mouth, brochures, personal advertising, social media groups, and online directories. For many, finding the agency or independent service provider is a real challenge as there isn’t a single place from which a company or worker can be obtained. It is also difficult to validate the credibility of the private service, as there is no obligation on behalf of agencies to be accredited. In addition, for some, cost plays an important factor. Many independent providers will charge less than agencies whose goals are driven by the profit motive. However, validating the credentials and trustworthiness of the service provider is complicated. It often takes numerous interviews and tries before finding consistent and reliable services. Those individuals who receive a referral/advice from friends or have professional knowledge of the health care system, are more easily able to obtain private care.

5. What services are received? And how much?

Public- PSW and/or nursing services are allocated to individuals in the public group. The number of hours per client is recorded in Table 2. in the results section. Findings reveal no relationship between the number of service hours provided and the actual need of the client (as per the Care Dependency Scale). This finding is consistent with the study conducted by Grant & Church (2015), which demonstrates a lack of uniformity among LHINs on the criteria to determine eligibility for care. Allocation of resources varies based on geographic location and is subject to judgement from the LHIN. Such findings have significant implications for caregivers whose majority of the day is consumed with direct/indirect care tasks as a result of limited supports. These conditions negatively impact health outcomes and place individuals in financially vulnerable positions due to the inability to maintain paid employment.

Private- All the individuals in the private group are purchasing PSW services. The number of hours purchased is recorded in Table 3. in the results section. Findings reveal that those individuals who require more care (as per care dependency scale) purchase more hours. When compared to the public group, the majority of these caregivers are able to maintain employment and receive opportunities for respite due to their ability to purchase care. As such, forgoing the economic vulnerability and physical/psychological burnout, reported by those in the public group.

6. What are the challenges in accessing home care services?

Public- The main challenges with accessing public home care services are difficulty in finding out about them in the first place and then having them initiated. The home care system is problematic to navigate and some are unaware of its existence. Those who are discharged from acute care with conditions requiring medical attention will often receive a referral to the LHIN directly from the hospital. However, there are many individuals with disabilities or those whose medical conditions worsen over time, that would greatly benefit from formal supports. Yet, the family physician often fails to direct clients/caregivers and there is no advertisement or *common knowledge* regarding accessing services.

In addition, even for individuals who know that home care in Ontario exists and are aware of how to contact their LHIN, the actual process of getting connected, receiving an assessment and then the services themselves often takes months. As some of the participants note, the province might not want individuals to know that services exist. Funding is limited and the majority of it is filtered through various administrative bodies for profit sake.

Private- Challenges with obtaining care from the private marketplace are different than those in the public system, because there is no single governing body (LHINs) that decides on where services will be contracted from. Main challenges reported by these caregivers include difficulty in finding a credible agency or independent service provider, their own financing capabilities, their schedules, and poor staffing. Agencies often require clients to purchase services in 3-4-hour blocks. However, for some, this is either too expensive or not required. In addition, hiring well trained knowledgeable workers is challenging for both publicly funded and privately financed agencies. As such, staffing can become problematic and frustrating for those waiting for timely and consistent care.

7. What is the experience dealing with agencies and their providers?

Public- Agencies and their providers vary in the quality of care that they deliver. On the public side, individuals usually have no say in what agency they will be receiving services from. An exception to this is living in a smaller region where there is a closer rapport established between the case manager and caregiver. These participants have been able to switch agencies and are overall much happier with their experience. Nevertheless, once an agency has a contract with the LHIN, they are only held accountable for the utilization of funding. They do not have to report on quality standards or client satisfaction. Thus, it is possible for different agencies to pay their providers varied fees, greatly impacting the worker's and client's satisfaction.

In general, some agencies may be more staffed then others, have better customer service and are overall genuinely more interested in delivering respectable care. Unfortunately, since contracted agencies receive funding regardless of their performance, and are also skewed by profit motive, the incentive to make improvements is often lacking.

Private- Similar to the public side, agencies and service providers vary in the quality of care that they deliver. However, privately financed agencies are dependent on their customers for continued business and thus are motivated to provide better services. Unfortunately, staffing is problematic and smaller agencies with poor marketing strategies many not have the capabilities to offer dependable care. Large well known corporations or those that have both funding from the LHIN and offer services for private pay, are more likely to succeed and be able to guarantee the delivery of services.

In terms of the actual workers, those who receive stable work hours and better pay are more satisfied with their job which translates to better performance. Finally, since services are paid for out-of-pocket, individuals have more weight to their voices. They can request an alternate service provider or choose to switch to a different agency at any time.

8. What would caregivers like to see improved in their experience?

Public- On the whole, caregivers would like the home care system to be easier to navigate. They want more information available to them regarding eligibility for services and how to get connected to their LHIN. Clients also wish for an easier transition between LHINs if they have moved and a direct line of contact with their case manager/agency supervisor. In addition, more hours based on care needs, consistency in care workers, matching of needs (gender, language), and better training in areas of dementia have been sited.

Private- As opposed to the public side, for the most part, the experiences with private care have been positive with satisfaction regarding consistency, completion of extra tasks and matching of needs being reported.

Caregivers would like to see a standardized accreditation for home care agencies offering private services and a single directory where all qualified agencies/service providers can advertise what they offer. The also wish for more transparency regarding credentials, rates of services, minimum number of hours that must be purchased and availability of workers.

9. How many service hours do caregivers think they require or would like?

Public- The number of hours required greatly depends on the care needs of the clients, their schedules as well as their personality. Some clients as well as caregivers prefer not to have strangers within the personal space of their homes for prolonged durations. At the same time, if a consistent and dependable worker is delivering the care, then more hours are certainly welcomed. In addition, the scheduling of hours is important as individuals have appointments and other daily happenings.

Private- Contrary to the public system, where caregivers struggle to obtain hours of services to match the needs of clients, those who can afford to pay for private services obtain as many hours as they wish/require. Others shop around to find cheaper rates or independent service providers that are willing to deliver care in shorter, 1-2 hour blocks.

10. Once services are initiated, do caregivers obtain the needed respite?

Public- With the exception of one participant, all report that there simply aren’t enough resources (hours and tasks completed) for them to have the opportunity for respite. When a service provider does attend, the caregiver must engage in other tasks including laundry, cooking, cleaning etc. In addition, due to the inconsistency in workers, establishing rapport and trust is problematic. Caregivers often provide orientation and supervision for every new worker that comes to the home.

Private- Contrary to the public system, the majority of the participants in this group do not engage in all care duties. They hire agencies or independent service providers that unlike with public care, consistently deliver the services. As such, these caregivers are able to obtain support, while establishing rapport and trust in the provision of care. In doing so, it is possible for these caregivers to maintain employment, and attain respite as needed. Understandably, those who are able to afford as many hours as required and are comfortable with others in the home, have the greatest advantage.

11. What are the unmet needs of caregivers?

Public- This question refers to the challenges caregivers face in their personal lives. All caregivers report feeling physically and emotionally exhausted. Many do not have opportunities to socialize or spend time with family and friends. Feelings of guilt, frustration, loss of identity, anxiety and depression tend to manifest themselves. In addition, individuals also report stresses associated with financial challenges. Only four of the twelve caregivers are able to maintain some form of employment and none can afford the private purchase of care services.

Private- Caregiving is challenging regardless of whether individuals can afford to pay for care. On the private side, caregivers are less physically exhausted as they do not engage in as many direct care tasks or reside with the clients (the majority). However, the grief associated with looking after a family member and the task of making sure that reliable services are provided, is emotionally draining. Financially those who can afford as many care hours as required and have a consistent provider, are more at peace. They are able to live independently, spend time with family/friends, have the extra assistance and/or maintain employment.

Table 5. presents a summary of the main findings from IFC experiences in both the publicly funded and privately financed groups.

Table 5. IFC Experiences

Publicly Funded Home Care Services	**Privately Finances Home Care Services**
Caregiving follows a structured routine	Caregiving follows a structured routine or is a managerial role
Difficulty finding out about and accessing services	Difficulty finding an agency or independent provider
Complexity in access when switching regions/LHINs	Various reasons for utilization: ineligibility for public, need to supplement public hours, need for more consistency in services, choice to forgo the public system
Care is dependent on the case manager/agency/service provider	Care is dependent on the agency/service provider
Limitations in the number of service hours allocated to clients, frequent cancellations	Can pay to receive as many hours as required. Must pay per 3-4 hour block (may be too expensive or not needed). Challenges with care due to staffing shortages
Poor matching of needs, poor consistency in services and task limitations	Can obtain consistency, matching of needs, and completion of extra tasks
Feelings of loss of identity, stress, anxiety, and depression. Little to no opportunity for respite. Financial difficulties.	Feelings of stress and depression. Have time for respite, social engagement, and employment. Less financial difficulties.
Client care needs met by caregivers vs. public home care services.	Client care needs met by privately purchased services

Chapter Seven
Discussion

Overview

The demand for home care services is steadily rising, especially given the aging population. Yet, within the topic of home care, little is known about the experiences of those who provide the bulk of the care, the IFC. Their experiences, however, can only be understood within the broader political and economic context. The rise of neoliberalism with its market-oriented reforms including decentralization, cost cutting in public supports and privatization of services, has impacted Ontario's home care system. The sector is coordinated by LHINs which contract mostly for-profit home care agencies for the actual delivery of care. With funding cutbacks and filtration through numerous administrative levels, the actual amount and quality of home care supports is compromised. In line with strategic neoliberal goals, IFC have the *choice* to forgo the public system and turn to the private marketplace in order to fulfil the care needs of their loved one. This illusion of *choice* creates inequities in health between those who can pay for private care and obtain respite from their caregiving duties, and those who are not privileged in this regard.

Acknowledging the overarching context, this study evolved from the need to understand the lived experiences of IFC with both publicly funded and privately financed home care services in and around the GTA. This research was the first of its kind to give voice to IFC, in a system where they mostly remain unheard. Through direct one-on-one interviews, this study provided an understanding of how/why IFC come to access either publicly funded and/or privately financed home care services in the first place. It also offered a deeper account of the complexities in interacting with the system, a wholesome description of the day to day lives of IFC, and the challenges in obtaining respite from the duties of care.

Utilizing descriptive phenomenology, this study addressed the research questions in the participants’ own words. Narratives and themes from the analysis of the transcripts provided the structure for describing the lived experience. There were numerous commonalities as well as singularities in the participants’ stories that captured the depiction of the experience in the time frame of the interview. These experiences are real for the moment, place, and individuals’ chosen. At another point in time or with a more diverse population, the data and analysis may be different. Fortunately, qualitative research, by nature, seeks the uniqueness and variability in a given phenomenon, without the boundaries of precision.

The credibility of a qualitative study is found in the descriptive dimensions of the experience so that others in a similar life situation would recognize it as their own story. All of the study participants were willing and grateful to tell their stories. Many of them noted that this was the first time that anyone was interested in listening to their experiences. All participants were hopeful and wanting for their voices to be heard and for changes to be made to improve the lives of other in similar circumstances.

To assure integrity, all of the taped interviews were listened to carefully, transcribed verbatim via software, and then re-read numerous times. Nvivo 12 qualitative data analysis software allowed for the clear organization of data. Bracketing was also an important factor in isolating personal experiences of caregiving. Keeping a reflexive journal of personal and caregiver reactions as they describe the phenomenon throughout the study facilitated bracketing.

Theoretical Frameworks in Relation to IFC Experiences

This study is influenced by the work of FP economists and highlights the impact of socioeconomic policies on states, markets and households as pertaining to the provision of paid and unpaid work. Examining these relations enables a conceptual understanding of inequities in health as stemming from the unequal division of labour in society which assigns both paid employment and unpaid household/care work to women (Armstrong & Armstrong, 2010). FPE acknowledges that women's unpaid domestic work remains unaccounted for and underappreciated in neoliberal regimes, limiting welfare supports, and constraining the conditions required for social reproduction. The FPE approach further draws on the SDOH framework, and considers how the organization, and distribution of SDOH such as gender, income, and health care services, impact health outcomes of those who are in disadvantaged positions along the socioeconomic hierarchy (Bryant, 2009).

In the home care sector, the introduction of competitive bidding, a market-based neoliberal reform, created high barriers to entry for providers, resulting in the delivery of services by a few large for-profit agencies. Those agencies that were able to afford the bidding process, and won contracts with CCAC's, ultimately increased the costs of their services (Randall & Williams, 2006). At the same time, the MOHLTC froze public funding to home care on a per capita basis in order to ration public resources (England, Eakin, Gastaldo, & McKeever, 2007). Such actions led to the filtering of limited funds through various administrative levels, promoted profit generation for providers, and ultimately diminished services to clients at a time of growing demand. In addition, agencies that received public contracts became accountable only for the utilization of funding. Reporting on quality standards or client satisfaction was and continues to not be required, resulting in variations in the quality of customer service and the delivery of services.

In both the public realm of the labour market and the private realm of the home, the paid and unpaid work of care is primarily dominated by women (Armstrong & Armstrong, 2010). As such, Ontario's home care reforms have greatly impacted the experiences of female formal and informal family care providers (England, Eakin, Gastaldo, & McKeever, 2007). In the formal economy, competition resulted in inequitable conditions for female employees by creating an environment with high job turnover, staffing shortages, lowered wages, limited to no benefits, and no job security. As a result, workers (nurses, PSW's) left the home care sector to find employment in more generously funded areas with more stable working conditions. The shortage of employees in the publicly funded home care system was voiced in the experiences of IFC, in the present study. Care is often inconsistent with varying providers coming in to service the client. Limited allocation of service hours, cancellations, and little possibility and attention to the matching of gender preference, language and/or personality were all noted.

In the private realm of the household, the role of caregiving is primarily taken on by a female spouse or daughter (Gruneir et al., 2013). In this study, eleven out of the twelve participants in the public group were female. Due to limited home care supports provided by the publicly funded system, only four IFC were able to maintain some type of employment and the rest were either retired or not able to work due to their caregiving roles. The day-to day lives of IFC depicted fairly rigid daily routines structured around the needs of the care recipient, leaving little opportunity for respite. Adding to this workload, all IFC were responsible for household chores and/or looking after other family members. Those who were of employment age, struggled financially and those who were retired had limited savings and could not afford to pay for extra private services. The one male participant was retired but had connections with the LHIN, and thus, was able to obtain many public care hours. To date, there are no policies in place that compensate IFC for loss of employment income or the work of caregiving, resulting in financial vulnerability, socioeconomic disadvantage, chronic stress and inequitable health outcomes.

In the households of IFC purchasing home care services from the private marketplace the majority of the individuals were female but unlike in the public group, were able to maintain employment, reside independently, engage with family/friends and obtain respite from their caregiving duties. This was especially the case for those IFC who took on a more managerial role of coordinating home care services as part of their daily caregiving duties. Interestingly, in half of the cases, the client was paying for the services out of their personal savings, which were likely substantial. Nevertheless, savings/income was not the only determinant to accessing privately financed care and many other decisive factors were noted.

To date, there is no one particular place where IFC can look up a reliable privately financed agency or independent service provider. It may be time consuming to search for and employ the desired services since agencies and providers vary in the quality of supports that they offer. On the private side, agencies are dependent on their customers for continued business and thus are motivated to provide better services. As such, efforts are made to match the client with a consistent service provider that is of preference and likable by the IFC. However, as in the publicly funded system, the pool of providers is limited, and the staffing of quality providers is challenging. Thus, posing difficulty in the completion of this task.

Furthermore, there is no formal regulatory oversight to ensure credibility of agencies/providers. Thus, IFC must carefully review their choice of hire in order to prevent fraudulent delivery of care. This is particularly important as the work involves attending to a vulnerable individual. Privately financed home care agencies also require individuals to purchase services in 3-4h blocks. For some, this can create a scheduling conflict with other appointments. Such lengthy service duration may also not be affordable or required and can impose on the personal space/time of clients and IFC.

In market- based societies where there are limited welfare supports, individuals bear the responsibility for attaining the care they require regardless of their social and economic conditions. As such, attention needs to be paid to both gender and income/financial resources when explaining accessibility to health services (Raphael, 2016). Although the work of caregiving is challenging for anyone, those who have greater financial safety nets, have better access to formal supports, and can continue to be employed and obtain respite. This is assuming that a reliable/consistent formal caregiver is hired and both the IFC and client are comfortable with their presence in the personal space of the home for prolonged duration (minimal blocks of time). In this study, it was demonstrated that female IFC who came from higher income families had much different experiences then those who were more economically disadvantaged (unable to work due to caregiving or had less household savings). With regards to the two men in the private group, one had a high reported income and the other, was on permanent disability. Neither one reported engaging in significant household duties (cleaning, cooking, etc.) or looking after the needs of other family members. This finding is consistent with previous research, highlighting the differential experiences of informal caregiving for men and women (Lee & Tang, 2015).

Implications of Quantitative and Qualitative Findings for Health Policy and Equity in LTC Reform

In LTC reform, the decisions come down to drawing boundaries between public and private and the appropriate role of the state in the financing and provision of these services (Baranek, 2000). Over the last few decades, the home care system has gone through many changes. With time, hospital restructuring and technological advancements have shifted acute care into the home, increasing the demand for services and confusion on how to obtain them (Landry et al., 2008). In addition, the emergence of competitive bidding with the creation of the CCACs, was a strategic neoliberal strategy which opened the doors to privatization and eased the responsibility of public funding on behalf of the province (England, Eakin, Gastaldo, & McKeever, 2007).

The consequences of decentralization and privatization were an increase in the costs of care and diminished publicly funded home care services to clients at a time of growing demand (England, Eakin, Gastaldo, & McKeever, 2007). To date, the home care sector remains underfunded and understaffed, placing an enormous burden of care on IFC, who are primarily women. Consequentially, research now demonstrates a rise in IFC distress, linked to both the difficult nature of caregiving and financial struggles. Yet, the unpaid work of household and care continues to be deemed *natural* and excluded from the SNA, thereby, contributing to its invisibility (United Nations, 1953; United Nations, 2009). Together with the rise of neoliberalism which seeks to minimize welfare supports, policies deliberately fail to address ways in which to better their lives of IFC and create more equitable health outcomes.

In this study the impact of Ontario's neoliberal reforms and the resulting consequences were voiced in the experiences of IFC. Since funding is limited, quantitatively we saw that care needs were not a determinant of how many hours would be allocated to service provision. As such, it is the responsibility of IFC to spend the majority of their day engaging in both direct and indirect care tasks. Qualitatively, IFC reported many challenges in accessing public care, and obtaining respite from their duties. In addition to struggling with physical and psychological burnout, the majority were not able to maintain employment, resulting in financial vulnerability.

Furthermore, understaffing in home care agencies due to poor working conditions and high job turnover in the sector, translated to less consistent care for clients and poor matching of needs. The inability to establish rapport with service providers and issues with cancellations/disruptions are extremely stressful to IFC who must carefully plan out their daily tasks and to clients who find any changes in routine detrimental to their emotional/physical needs.

As discussed earlier, market competition had opened the doors to privatization. As such, IFC/clients who find the public system to be inadequate have the *choice* to turn to the private marketplace. This illusion of *choice* of where to seek services and how much, is a primary goal of strategic neoliberal reforms which seek to minimize public supports (McGregor, 2001). Quantitatively, this trend was signified by the relationship between increased care needs and hours of private care purchased. The higher the needs were of the client; the more service provision was obtained. Thus, need and care were more closely matched by the services provided in the private home care system. This finding was contrary to the IFC in the public system, who did not have the *choice* to turn to the private marketplace and thus, provided the majority of the care themselves.

Aside from the numerous hurdles in finding a reliable and consistent agency/service provider, the ability to obtain services privately was voiced positively by IFC. Individuals who could afford the most services and were not concerned with strangers in the home, were able to select providers of their choice, while scheduling appointment times in accordance to their needs. As a result of having consistency and trust in service provision, these IFC were able to maintain paid employment, reside independently, obtain respite and have less physical /psychological distresses.

On the whole, this study has shed light on the limited knowledge of IFC experiences with publicly funded home care and the lacking knowledge with privately financed services. At present, the public system is underfunded, understaffed, and demonstrates inadequate quality of care. While the findings demonstrate the many challenges with the public sector and positive aspects of obtaining private care, it is not suggested that privatization in the sector is superior. On the contrary, private services are unaffordable by the majority of the population and go against the principles we value about our Canadian health care system- Accessibility and Universality. As we have learned from the voices in his study, privatization results in inequities in health between those who can access the services and those who cannot. This trend will only continue to become more evident with the growing demand for home care.

Changes in the LTC sector continue. Within a short period of time we witnessed the amalgamation of the CCACs into the LHINs and now, the upcoming dissolution of the LHINs altogether. The rein of Super Agency, Ontario Health, has come and with it potential mergers, transfers and further privatization, possibly further worsening the situation in the publicly funded home care sector (Ontario Health Coalition, 2019). The exact impact of *The People's Health Care Act or Bill 74* and its impact on the services to clients and experiences of IFC, remains to be seen. Nevertheless, since our public home care system is of growing demand, below are recommendations for improvement as per the findings of this study.

Recommendations

The following recommendations can improve the lives of IFC. They stem from the current happenings and visible inadequacies in the home care system and from the voices of IFC.

1. At this time the home care sector receives about 5.1 percent of Ontario's total health budget. Although it is difficult to provide an exact estimate of how much funding should increase, the calculation should be based on current demand for services per region. As previously noted, the government plans to invest an additional $124 million into the home care sector. How this amount is calculated and whether it is based on actual need is unclear.

2. Funding and services should be allocated based on need. As such, a standardized, objective tool can be developed and used by all case managers to determine the number of hours a client is eligible for. The scoring for this tool is to be consistent across all regions. The calculation should follow a simple formula, that translates the care needs of the client into the hours of services that are to be allocated. This tool can make it easier to estimate how much funding should be dedicated to the home care sector as per the above recommendation. In general, the provision of sufficient formal care, is an important step towards promoting respite for IFC.

3. Agencies should provide better working conditions for service workers including, more full- time positions, guaranteed work hours and employment benefits. By making employment more appealing, they may be able to recruit a range of providers including both males and females, individuals from different cultural backgrounds and areas of expertise.

In doing so, these agencies can become better equipped to provide consistency in service provision, and better matching of needs (gender preference, language) to clients. This goes for both publicly funded and privately financed agencies.

4. Many residents of Ontario are not aware that the home care system exists or how to obtain the services. Advertisements or information in physicians' offices should be made visible and available to all patients. A television infomercial can be broadcasted on local networks to spread awareness about the existence of home care and services offered.

5. Transitioning between regions should be made simpler for individuals who relocate. If an assessment has already been conducted in one region, and the number of service hours have been allocated (based on a standardized tool as per recommendation #2), by utilizing e-health, a centralized electronic system can be used to convey the information to the new case manager in charge. Thus, removing the need for a new assessment, excess administrative costs, and delays in accessing care.

6. A single accreditation body should be established that certifies both publicly funded and privately financed home care agencies. This governing body should undertake measures that enforce and monitor the quality of services provided by agencies. Agencies should demonstrate markers such as excellence in customer service, timely delivery of care, and client satisfaction.

7. A centralized directory should be established that lists all accredited home care agencies and independent service providers searching for work (including their credentials, language, and areas of expertise). If this service exists then agencies (publicly funded and privately financed) and clients/caregivers, can more easily recruit providers in accordance to their needs.

8. IFC require support to aid with physical, psychological and financial challenges. To-date, there are many caregiver support groups and online resources such as the *Mental Health Caregiver Guide*, that can aid in the difficult journey of caregiving (Turcotte, 2016). Unfortunately, attending support groups or looking for/reading through guides takes time, a luxury which many do not possess. As such, the receipt of sufficient amount of care hours (publicly or privately) based on client needs are required in order to have opportunities to benefit from available resources.

In addition, since the home care sector heavily relies on the dedication of IFC, the work of caregiving should be compensated. Those individuals who must reduce their work hours, or leave employment in order to undertake a caregiving role, ought to receive alternative compensation. IFC who are retired or have not previously been employed should also receive some compensation for their time and energy. Decreasing or removing the stress associated with financial struggles is a critical step in promoting equitable health outcomes.

Study Limitations

As a sole, unfunded researcher collecting data, I am aware that the small-scale nature of this study may not be fitting for the transferability of findings. By contrast, the findings of larger-scale, funded research projects conducted with a team of researchers, have the potential to produce greater validity. However, such projects are expensive and time consuming, presenting their own limitations. Overall, the findings of this study have strong implications for policy and their relevance is up to the reader. My aim was to wholly understand, shed light and draw conclusions on IFC’ experiences with both the publicly funded and privately financed home care systems in and around the GTA. This was the first study of its kind to address this topic.

Future and Other Relevant Research

Future research can examine the experiences of a larger sample of IFC from varying cultural and economic backgrounds (the intersection of gender with race, age, and class). It can also examine these experiences in different regions in Ontario, since funding varies geographically. Unfortunately, this study only captured two women in the sandwich generation. Those are the individuals who care for aging parents while bringing up their own children. It is likely that women in this generation are the most burdened with dual workdays and are too busy to share their experiences through research. Finally, it will be interesting to analyze the effects of the newly established super agency, Ontario Health, for its impact on the home care sector.

Across Ontario there have been various initiatives to implement direct funding so that clients can choose the type of care they require. For example, in 2005/2006 the Ministry of Community and Social Services implemented the passport program (Ministry of Community and Social Services, 2011). This program helps adults with developmental disabilities become engaged in the community, hire support workers of their choice as well as provides respite for informal caregivers. The maximum annual amount that the passport program funds is $35,000 per individual (Developmental Services, 2014).

More recently, the MOHLTC has launched a new self-directed care program, Family-Managed Home Care (Home and Community Care, 2017). Under this initiative, clients or their decision-makers receive funding to directly purchase home care or employ care providers of their choice. To be eligible for this program clients must belong to either of the following groups: children with complex medical needs, adults with acquired brain injuries, eligible home-schooled children, and clients in extraordinary circumstances. Assessments are conducted by the LHINs and clients/decision makers must report back regarding the spending of their funding. In general, the program provides more autonomy to individuals and more control over the decisions pertaining to their own care. As such, examining the experiences of clients and IFC with these programs to understand how they choose to spend funding, how this impacts caregiver respite and the influence on health and well-being is an interesting venture.

Postscript

This study was conducted prior to the COVID-19 pandemic. As such, the experiences of IFC may not be representative of the current situation. Nevertheless, it is undoubtable that safety precautions such as social distancing and the closure of non-essential services have negatively impacted the lives of IFC and their loved ones. For example, if a home care client has suspected or confirmed case of COVID-19, their supports are likely to be delayed (Ministry of Health, 2020). In turn, increasing the burden of care and risk for the IFC (especially if they do not have personal protective equipment-PPE).

In addition, scarce and expensive PPE may be unattainable by some service providers who may consequently choose to stop working at this time or not visit particular areas in the GTA where more cases have emerged. It is thus probable that understaffing and potential closures of agencies, have left many individuals with unmet needs for care. The impact on IFC experiences as stemming from the developing (and future) COVID-19 regulations in the home care sector should be investigated.

Bibliography

Al-Busaidi, Z. Q. (2008). Qualitative research and its uses in health care. *Sultan Qaboos University Medical Journal*, *8*(1), 11.

Armstong, P. (1997). Women's paid and unpaid work. In S. B. Boyd (Ed.), Challenging the public/private divide: Feminism, law, and public policy (pp. 37-61). Toronto, Canada: University of Toronto Press.

Armstrong, P. , & Armstrong, H. (2004). *Thinking it through: Women, work and caring in the new millennium*. In K. Grant et al. (Eds.), Caring for/caring about: Women, home care, and unpaid caregiving (pp. 5-43). Aurora, Ontario, Canada: Garamond Press.

Armstrong, P., & Armstrong, H. (2010). *The double ghetto: Canadian women and their segregated work*. Don Mills, ON: Oxford University Press.

Armstrong, P., & Connelly, M. P. (1989). Feminist political economy: An introduction. *Studies in Political Economy*, *30*(1), 5-12.

Aronson, K. J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology*, 48(1), 74-80.

Aronson, J., & Neysmith, S. M. (1997). The retreat of the state and long-term care provision: Implications for frail elderly people, unpaid family carers and paid home care workers. *Studies in Political Economy*, *53*(1), 37-66.

Association of Municipalities of Ontario. (2011). *Coming of Age: The municipal role in caring for Ontario's seniors*. Retrieved from https://www.amo.on.ca/AMO-PDFs/Reports/2011/2011_Coming_of_Age_the_Municipal_Role_in_Caring_fo.aspx

Baranek, P.M. (2000). Long term care reform in Ontario: The influence of ideas, institutions and interests on the public/private mix. Unpublished doctoral dissertation, *National Library of Canada.*

Beck, C. T., Keddy, B. A., & Cohen, M. Z. (1994). Reliability and validity issues in phenomenological research. *Western Journal of Nursing Research*, *16*(3), 254-267.

Boggatz, T., Dijkstra, A., Lohrmann, C., & Dassen, T. (2007). The meaning of care dependency as shared by care givers and care recipients: a concept analysis. *Journal of Advanced nursing*, *60*(5), 561-569.

Brannen, C. (2006). Women's Unpaid Caregiving and Stress. *Centres of Excellence for Women's Health Research Bulletin*, *5*(1), 12-13.

Brazil, K., Thabane, L., Foster, G., & Bédard, M. (2009). Gender differences among Canadian spousal caregivers at the end of life. *Health & Social Care in the Community*, *17*(2), 159-166.

Briggs, A. (2006). The welfare state in historical perspective. In Pierson, C., & Castles, F. G. (Eds.) The welfare state reader (pp. 16-29). Malden, USA: Polity Press.

Browne, I., & Misra, J. (2003). The intersection of gender and race in the labor market. *Annual review of sociology*, *29*(1), 487-513.

Bryant, T. (2009). Housing & income as social determinants of women’s health in Canadian cities. Retrieved from: https://tspace.library.utoronto.ca/bitstream/1807/17683/1/bryant.pdf

Bryden, C. (n.d). *Unregulated care providers*. Retrieved from: https://rnao.ca/sites/rnao-ca/files/Working_with_Unregulated_Care_Providers.pdf

Byun, E., Lerdal, A., Gay, C. L., & Lee, K. A. (2016). How adult caregiving impacts sleep: A systematic review. *Current sleep medicine reports*, *2*(4), 191-205.

Cameron, J. I., Herridge, M. S., Tansey, C. M., McAndrews, M. P., & Cheung, A. M. (2006). Well-being in informal caregivers of survivors of acute respiratory distress syndrome. *Critical care medicine,* 34(1), 81-86.

Canadian Home Care Association. (2014). *Pre-budget consultation: 2015 budget.* Retrieved from: http://www.parl.gc.ca/Content/HOC/Committee/412/FINA/WebDoc/WD6615327/412_FINA_PBC2014_Briefs/CanadianHomeCareAssociation-e.pdf

Canadian Home Care Association. (2016). *The National Voice of Homecare*. Retrieved from http://www.cdnhomecare.ca/content.php?sec=5

Carcary, M. (2009). The Research Audit Trial – Enhancing Trustworthiness in Qualitative Inquiry. *The Electronic Journal of Business Research Methods*, *7*(1), 11-24.

Central East Local Health Integration Network. (2016). *Central East CCAC Response to Patient First Consultation.* Retrieved from: http://healthcareathome.ca/centraleast/en/news/Pages/Central-East-CCAC-Response-to-Patient-First-Consultation.aspx

Chan, Z. C., Fung, Y. L., & Chien, W. T. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process?. *The Qualitative Report*, *18*(59),1-9.

Chang, C. F., & White-Means, S. I. (1991). The men who care: An analysis of male primary caregivers who care for frail elderly at home. *Journal of Applied Gerontology, 10*(3), 343-358.

Chapman, A. R. (2010). The social determinants of health, health equity, and human rights. *Health and Human Rights,* 12(2), 17-30.

Closing the Gap Healthcare. (2016). *Healthcare in Ontario: How does it Work and How is it Funded?* Retrieved from: https://www.closingthegap.ca/guides/healthcare-in-ontario-how-does-it-work-and-how-is-it-funded/

Closing the Gap Healthcare. (2018). *Home Care in Ontario: How to Choose a Provider That's Right for You*. Retrieved from: https://www.closingthegap.ca/guides/home-care-in-ontario-how-to-choose-a-provider-thats-right-for-you/

Coburn, D. (2010). *Health and health care: Political economy perspective*. In T. Bryant, D. Raphael & M. Rioux (Eds.), Staying alive: Critical perspectives on health, illness, and health care (2nd ed.) (pp. 65-92). Toronto, ON: Canadian Scholars' Press Inc.

Cochrane, J. J., Goering, P. N., & Rogers, J. M. (1997). The mental health of informal caregivers in Ontario: an epidemiological survey. *American Journal of Public Health*, 87(12), 2002-2007.

Comfort Life. (N.d). *Home Care Costs & Funding Options in Canada*. Retrieved from: https://www.comfortlife.ca/retirement-community-resources/home-care-cost

Community Care Access Centre. (2015). *Provincial Fast Facts.* Retrieved from: http://healthcareathome.ca/torontocentral/en/Who-We-Are/About-CCAC/fast-facts

Crawley, M. & Janus, A. (2019). *Ford government creating Ontario Health super-agency. Retrieved* from: https://www.cbc.ca/news/canada/toronto/doug-ford-ontario-health-super-agency-lhin-cancer-care-1.5032830

Developmental Services. (2014). Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers. Retrieved from:

https://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/passport/Passport_Program_Guidelines-en.pdf

Dijkstra, A., Smith, J., & White, M. (2006). *Measuring care dependency with the Care Dependency Scale (CDS)—a manual*. Retrieved from: https://www.umcg.nl/SiteCollectionDocuments/research/institutes/SHARE/assessment%20tools/CDS%20manual%20english.pdf

Doyal, L. (1995). *What makes women sick: Gender and the political economy of health.* Chapel Hill, NC: Rutgers University Press.

Draaisma, M. (2018). *Priced In: Not everybody can afford to leave the GTA as cost of living soars, advocates say.* Retrieved from: https://www.cbc.ca/news/canada/toronto/priced-in-minimum-wage-workers-high-cost-living-gta-1.4844679

Drentea, P. (2007). *Caregiving.* Retrieved from: http://philosociology.com/UPLOADS/_PHILOSOCIOLOGY.ir_Blackwell%20Encyclopedia%20of%20Sociology_George%20Ritzer.pdf

Driever, M. J. (2002). Are evidenced-based practice and best practice the same?. *Western Journal of Nursing Research*, *24*(5), 591-597.

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

Gallicchio, L., Siddiqi, N., Langenberg, P., & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International journal of geriatric psychiatry*, *17*(2), 154-163.

Gerstel, N., & Gallagher, S. K. (2001). Men's caregiving: Gender and the contingent character of care. *Gender & Society, 15*(2), 197-217.

Gibbs, G. (2003). Doing phenomenological analysis using NVivo. In: *Strategies in Qualitative Research Conference, 8th-9th May 2003*, University of London

Giorgi, A. (1970). *Psychology as a human science: A phenomenologically based approach*. New York: Harper & Row.

Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Pittsburg, PA: Duquesne University.

Girgis, A., Lambert, S., Johnson, C., Waller, A., & Currow, D. (2012). Physical, Psychosocial, Relationship, and Economic Burden of Caring for People with Cancer: A Review. *Journal of Oncology Practice, 9*(4): 197–202.

Gkiouleka, A., Huijts, T., Beckfield, J., & Bambra, C. (2018). Understanding the micro and macro politics of health: Inequalities, intersectionality & institutions-A research agenda. *Social Science & Medicine, 200,* 92-98.

Glauser, W., Tierney M., & Bournes, D. (2016). *Ontario's ambitious Patients First legislation met with hope and skepticism.* Retrieved from: https://healthydebate.ca/2016/09/topic/patients-first-legislation-ontario.

Government of Ontario. (2020). *Regulated Health Professions Act*, 1991. Retrieved from: https://www.ontario.ca/laws/statute/91r18

Grant, K., & Church E. (2015). *No Place Like Home? Investigating Ontario's Home Care Shortcomings*. Retrieved from http://www.theglobeandmail.com/news/national/no-place-like-home-investigating-ontarios-home-care-shortcomings/article25409974/

Gruneir, A., Forrester, J., Camacho, X., Gill, S. S., & Bronskill, S. E. (2013). Gender differences in home care clients and admission to long-term care in Ontario, Canada: a population-based retrospective cohort study. *BMC Geriatrics*, 13(1), 48-59.

Groenewald, T. (2004). A phenomenological research design illustrated. *International journal of qualitative methods*, *3*(1), 42-55.

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

Hamill, C., & Sinclair, H. (2010). Bracketing-practical considerations in Husserlian phenomenological research. *Nurse Researcher (through 2013*), *17*(2), 16.

Hamilton, L. (n.d). *Personal Support Worker Scope of Practice.* Retrived from: http://www.psno.ca/uploads/1/0/1/9/10197937/what_can_a_psw_do.pdf

Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health*, *18*(3), 271-283.

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

Health Quality Ontario. (2016). The reality of caring: distress among the caregivers of home care patients. Retrieved from: https://www.hqontario.ca/Portals/0/documents/system-performance/reality-caring-report-en.pdf

Health Quality Ontario. (2018). *Measuring Up 2018: A yearly report on how Ontario's health system is performing*. Retrieved from http://www.hqontario.ca/Portals/0/Documents/pr/measuring-up-2018-en.pdf

Health Quality Ontario. (2019). *Caregiver distress: a crisis grows.* Retrieved from: https://www.hqontario.ca/Blog/system-performance/caregiver-distress-a-crisis-grows

Hirdes, J. P., Freeman, S., Smith, T. F., & Stolee, P. (2012). Predictors of caregiver distress among palliative home care clients in Ontario: evidence based on the interRAI Palliative Care. *Palliative & Supportive Care*, 10(3), 155-163.

Hofrichter, R. (2003). The politics of health inequities: Contested terrain. In R. Hofrichter (Ed.), *Health and social justice: A reader on ideology, and inequity in the distribution of disease* (pp. 1-56). San Francisco, CA: Jossey Bass.

Home and Community Care. (2017). Family-Managed Home Care. Retrieved from: http://healthcareathome.ca/northeast/en/Getting-Care/family-managed-home-care

Home and Community Care. (2017). *Frequently asked questions*. Retrieved from: http://healthcareathome.ca/hnhb/en/Getting-Care/Patient-and-Caregiver-Resources/Frequently-Asked-Questions

Home Care Ontario. (2011). *Facing the Facts*. Retrieved from: https://www.homecareontario.ca/docs/default-source/Family-Caregiving/facing-the-facts-what-do-we-know-about-families.pdf?sfvrsn=6

Home Care Ontario. (2014). *Statement on access to home care service delivery.* Retrieved from: https://www.homecareontario.ca/about-us/access-to-home-care

Home Care Ontario. (2017). *Facts & figures- publically funded home care*. Retrieved from: https://www.homecareontario.ca/home-care-services/facts-figures/publiclyfundedhomecare

Hudon, T. (2016). *Visible minority women*. Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/en/pub/89-503-x/2015001/article/14315-eng.pdf?st=6EZDg6dD

Husserl, E. (1962). *Ideas: General introduction to pure phenomenology.* New York: Collier Books.

John, W. S., & Johnson, P. (2000). The pros and cons of data analysis software for qualitative research. *Journal of nursing scholarship, 32*(4), 393-397.

Kalenteridis, K. (2017). Caring About Home Care: A Framework for Improvement in Ontario. Retrieved from: https://tspace.library.utoronto.ca/bitstream/1807/82732/1/Kalenteridis_2017_Caring%20About%20Home%20Care

Koch, T. (2006). Establishing rigour in Qualitative Research: the decision trail. *Journal of Advanced Nursing*. *53*(1), 91-103.

Kroenke, C. H., Hankinson, S. E., Schernhammer, E. S., Colditz, G. A., Kawachi, I., & Holmes, M. D. (2004). Caregiving stress, endogenous sex steroid hormone levels, and breast cancer incidence. *American journal of epidemiology*, *159*(11), 1019-1027.

Landry, M. D., Jaglal, S., Wodchis, W. P., Raman, J., & Cott, C. A. (2008). Analysis of factors affecting demand for rehabilitation services in Ontario, Canada: a health-policy perspective. *Disability and Rehabilitation*, 30(24), 1837-1847.

LeBaron, G. (2010). The political economy of the household: Neoliberal restructuring, enclosures, and daily life. *Review of International Political Economy*, *17*(5), 889-912.

Lee, Y., & Tang, F. (2015). More caregiving, less working: Caregiving roles and gender difference. *Journal of Applied Gerontology*, *34*(4), 465-483.

Lenhard, W. & Lenhard, A. (2014). *Hypothesis Tests for Comparing Correlations*. Retrieved from: https://www.psychometrica.de/correlation.html.

Lexico. (2020). Formal. Retrieved from: https://www.lexico.com/en/definition/formal

Lilly, M. (2011). The hard work of balancing employment and caregiving: what can Canadian employers do to help? *Health Policy, 7*(2): 23–31.

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative health research, 14*(5), 726-735.

Lum, J. M., Sladek, J., & Ying, A. (2015). *Ontario personal support workers in home and community care: CRNCC/PSNO survey results*. Canadian Research Network for Care in the Community. Retrieved from: https://www.ryerson.ca/content/dam/crncc/knowledge/infocus/factsheets/InFocus-Ontario%20PSWs%20in%20Home%20and%20Community%20Care.pdf

Luxton, M., & Bezanson, K. (Eds.). (2006). *Social reproduction: Feminist political economy challenges neo-liberalism*. Montreal and Kingston. McGill-Queen's Press-MQUP.

Lyon, D., & Glucksmann, M. (2008). Comparative configurations of care work across Europe. *Sociology*, *42*(1), 101-118.

Madjar, I. (2016). *Giving comfort and inflicting pain*. New York, NY: Routledge.

Madore, O. (2000). *The Canada Health Act: Overview and Options*--Rev. Library of Parliament, Parliamentary Research Branch. Retrieved from: http://www.res.parl.gc.ca/Content/LOP/ResearchPublications/944-e.htm.

Mapp, T. (2008). Understanding phenomenology: the lived experience. *British Journal of Midwifery, 16*(5), 308-311.

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

Merriam-Webster's. (2020). Definition of dependency. Retrieved from: https://www.merriam-webster.com/dictionary/dependency

Merleau-Ponty, M. (1962). *The phenomenology of perception*. London: Routledge & Kegan Paul.

Messing, K., & Ostlin, P. (2006). Gender equality work and health: a review of the evidence. Retrieved from: https://apps.who.int/iris/bitstream/handle/10665/43311/9241593539_eng.pdf?ua=1

Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian Facts*. Toronto, Ont.: York University School of Health Policy and Management.

Ministry of Community and Social Services. (2011). Passport guidelines. Retrieved from: http://www.ontla.on.ca/library/repository/mon/25007/311480.pdf

Ministry of Health. (2020). COVID-19 guidance: home and community care providers. Retrieved from: http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_home_community_care_guidance.pdf

Ministry of Health and Long Term Care. (2017). *Ministry Plans*. Retrieved from: http://www.health.gov.on.ca/en/common/ministry/publications/plans/ppar17/

Mish, F. C. (2002). *Merriam-Webster's collegiate dictionary* (10th ed.). Springfield, Massachusetts: Merriam-Webster.

Munhall, P. L. (1994). *Revisioning phenomenology: Nursing and health science research*. New York: National League for Nursing.

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

OECD. (2011). *Health at a Glance 2011: OECD Indicators*, OECD Publishing.

Ontario. (2019). *The People's Healthcare Act*. Retrieved from: https://www.ontario.ca/laws/statute/S19005

Ontario Health Coalition. (2015). *The Care We Need.* Retrieved from http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf

Ontario Health Coalition. (2019). *Release & Analysis: Health Care Omnibus Bill Sets Up Ontario for Health System Mega-Mergers & Privatization: Worse than the Leaked Draft, Health Coalition Warns.* Retrieved from: https://www.ontariohealthcoalition.ca/index.php/release-analysis-health-care-omnibus-bill-sets-up-ontario-for-health-system-mega-mergers-privatization-worse-than-the-leaked-draft-health-coalition-warns/

Ontario Home Care Association. (2008). *Ontario Home Care System in 2008: A Growing History of Quality and Excellence*. Retrieved from https://www.homecareontario.ca/docs/default-source/position-papers/position-papers/ontario-home-care-overview.pdf?sfvrsn=4

Ontario Newsroom. (2016). *Ontario passes legislation that delivers better health care for families*. Retrieved from: https://news.ontario.ca/mohltc/en/2016/12/ontario-passes-legislation-that-delivers-better-health-care-for-families.html

Ontario Secretariat for Social Development. (1981). *The elderly in Ontario: An agenda for the 80s*. Report of the task force on aging. Toronto, Ontario.

Onwuegbuzie, A. J., & Leech, N. L. (2007). A call for qualitative power analyses. *Quality & Quantity*, *41*(1), 105-121.

Oxford English Dictionary. (2011). *Caregiving*. Oxford University Press. Retrieved from http://oxforddictionaries.com/view/entry/m_en_us1230846#m_en_us1230846.003

Phenomenology. (2015). *New World Encyclopedia*. Retrieved from: http://www.newworldencyclopedia.org/entry/Phenomenology

Pinquart M. & Sörensen S. (2003). Differences Between Caregivers and Noncaregivers in Psychological Health and Physical Health: A Meta-Analysis. *Psychol Aging 18*(2):250-67.

Polkinghorne, D. E. (1989). *Phenomenological research methods*. In R. S. Valle & S. Halling (Eds.), *Existential-phenomenological perspectives in psychology: Exploring the breadth of human experience* (pp. 41-60). New York, NY, US: Plenum Press.

Randall, G. (2007). The reform of home care services in Ontario: Opportunity lost or lesson learned?. *Canadian Journal of Occupational Therapy*, *74*(3), 208-216.

Randall, G. E., & Williams, A. P. (2006). Exploring limits to market-based reform: managed competition and rehabilitation home care services in Ontario. *Social Science & Medicine*, 62(7), 1594-1604.

Raphael, D. (2002). Poverty, income inequality, and health in Canada. CSJ Foundation for Research and Education. Retrieved from: http://www.socialjustice.org/uploads/pubs/PovertyIncomeInequalityandHealthinCanada.pdf

Raphael, D. (2016). Social Determinants of Health: Canadian Perspectives, 3rd ed. Toronto, Canada: Canadian Scholars Press.

Ratcliff, D. (2008). Qualitative data analysis and the transforming moment. *Transformation, 2/3*(25), 116-133.

Reiners, G. M. (2012). Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research. *Journal of Nursing Care, 1*(5),1-3.

Riley, M. (2008). *A Feminist Political Economic Framework*. Retrieved from https://pdfs.semanticscholar.org/752a/93623d25ab857f420645631d8d2bc38a2cb7.pdf?_ga=2.209374993.2049784603.1571351877-352107489.1571351877

Romanow R. (2002). *Building on values: The future of health care in Canada.* Retrieved from http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf

Schumacher, L. A. (2010). The caregiver's journey: a phenomenological study of the lived experience of leisure for caregivers in the sandwich generation who care for a parent with dementia. The University of Iowa.

Sackett, D. L., Rosenberg, W. M., Gray, J. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: what it is and what it isn't. *Br Med J, 312*, 71-72.

Sharma, N., Charrabarti, S. & Grover, S. (2016). Gender differences in caregiving among family caregivers of people with mental illnesses. *World Journal of Psychiatry, 6* (1): 7-17.

Sloan, A., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: the philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity*, 48(3), 1291-1303.

Snelling. (2005). When menopause and caregiving collide. Retrieved from: https://www.nextavenue.org/when-menopause-and-caregiving-collide/

Sohn, B. (2017). Phenomenology and Qualitative Data Analysis Software (QDAS): A Careful Reconciliation. *Forum Qualitative Social Research, 18*(1), 287-320.

Starr, P. (1988). The meaning of privatization. *Yale Law & Policy Review*, *6*(1), 6-41.

Statistics Canada. (2012). *Portrait of Caregivers*. Retrieved From: https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.htm#a10

Statistics Canada. (2016). Population and Dwelling Count Highlight Tables, 2016 Census. Retrieved from: https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/hlt-fst/pd-pl/Table.cfm?Lang=Eng&T=101&S=50&O=A

Statstutor. (n.d). Spearman's correlation. Retrieved from: http://www.statstutor.ac.uk/resources/uploaded/spearmans.pdf

Stenberg U., Ruland CM., & Miaskowski C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-oncology*, *19*(10), 1013–1025.

Stewart, D. (1974). *Exploring phenomenology: A guide to the field and its literature.* Athens, OH: Ohio University Press.

Swanberg, J. E. (2006). Making it work: Informal caregiving, cancer, and employment. *Journal of Psychosocial Oncology*, *24*(3), 1-18.

Sweet, M., & Doggett, J. (2015). *On the importance of connecting health services research, policy and practice.* Retrieved from: https://croakey.org/on-the-importance-of-connecting-health-services-research-policy-and-practice/

Tal, B., & Mendes R. (2017). Who cares: The economics of caring for aging parents. Retrieved from: https://mma.prnewswire.com/media/508959/Canadian_Imperial_Bank_of_Commerce_Caring_for_aging_parents_cost.pdf

Tariq, S., & Woodman, J. (2013). Using mixed methods in health research. *JRSM short reports*, *4*(6),1-8.

The British Academy (n.d). Mann Whitney tests in SPSS (Practical). Retrieved from: https://www.bristol.ac.uk/cmm/media/research/ba-teaching-ebooks/pdf/Mann%20Whitney%20-%20Practical.pdf

The Change Foundation. (2016). *Stories shared, voices heard: Ontario's Family Caregivers.* Retrieved from: http://www.changefoundation.ca/stories-shared-family-caregiver-report/

Timmermans, S., & Berg, M. (2010). *The gold standard: The challenge of evidence-based medicine and standardization in health care*. Temple University Press.

Turcotte, M. (2015). *Family caregiving: What are the consequences?* Retrieved from https://www150.statcan.gc.ca/n1/pub/75-006-x/2013001/article/11858-eng.htm

Turcotte, J. (2016). *Mental Health Caregiver Guide*. Retrieved from: http://www.ottawapublichealth.ca/en/public-health-topics/resources/Documents/mental_health_caregiver_guide_en.pdf

United Nations. (1953). *A system of national accounts and supporting tables*. Retrieved from: https://unstats.un.org/unsd/nationalaccount/docs/1953SNA.pdf

United Nations. (2009). *Caregiver burden must be valued shared supported by governments as crucial to sustaining society, building human capital, women's commission told*. Retrieved from: https://www.un.org/press/en/2009/wom1715.doc.htm

United Nations. (2020). *Historic versions of the System of National Accounts*. Retrieved from: https://unstats.un.org/unsd/nationalaccount/hsna.asp

Vagle, M. D. (2014). *Crafting phenomenological research*. Walnut Creek, CA: Left Coast Press.

Van Den Heuvel, W. (1976). *The meaning of dependency.* In: J.M.A. Munnichs & W.J.A. van den Heuvel (eds). Dependency or interdependency in old age (pp. 162-173). Springer, Dordrecht.

Vanier. (2017). *Infographic: women, caregiving and work in* Canada. Retrieved from https://vanierinstitute.ca/infographic-women-caregiving-work-canada/

VON. (2018). *History*. Retrieved from http://von.ca/en/history.

Williams, A. M. (1996). The development of Ontario's Home Care Program: A critical geographical analysis. *Social Science & Medicine*, 42(6), 937-948.

Wojnar, D. M., & Swanson, K. M. (2007). Phenomenology: an exploration. *Journal of holistic nursing*, *25*(3), 172-180.

Yin, R.K. (2014). *Case study research: Design and methods*. Los Angeles, CA: Sage.

Appendix A

Survey Questionnaire

Please select the most appropriate answer below. You may highlight your answer or put an (X) beside it.

Caregiver's Name:

1. How old are you?

☐ 16 years to 19 years
☐ 20 years to 24 years
☐ 25 years to 34 years
☐ 35 years to 44 years
☐ 45 years to 54 years
☐ 55 years to 64 years
☐ 65 years to 74 years
☐ 75 years to 84 years
☐ 85 years to 94 years
☐ 95 years and over

2. Marital status:

☐ Single – never married
☐ Married (legal and common law)
☐ Separated
☐ Widowed
☐ Divorced
☐ Other – specify: ______________________________

3. What is your gender?

☐ Male
☐ Female
☐ Other – specify: ______________________________

4. What is your sexuality?

☐ **heterosexual (straight)**
☐ Homosexual
☐ Bisexual
☐ Queer
☐ Asexual

5. Do you have children?

☐ Yes
☐ No
☐ Other – specify: ____________________________

6. Are you a single parent?
☐ Yes, number of children__________ Age of children_____________
☐ No
☐ Other– specify: __________________________________

7. Do you have grandchildren?

☐ Yes
☐ No
☐ Other – specify: __________________________

8. Were you born in Canada?

☐ Yes - Skip to Question 10
☐ No
☐ Don't know
☐ Refused

9. What country were you born in?

☐ Specify: __ ___________________________

☐ Refused

10. How old were you when you came to Canada?

☐ Specify: _____________________________
☐ Refused
☐ Don't know

11. Are you a …. [Check one]

☐ Canadian Citizen
☐ Landed Immigrant
☐ Convention refugee
☐ Temporary status
☐ Other – specify: _____________________________
☐ Don't know
☐ Refused

12. With which racial or cultural group do you most identify? [Check all that apply]

☐ White, Caucasian
☐ Black, African-Canadian
☐ Black, Caribbean-Canadian
☐ First Nations/Aboriginal (e.g. Cree, Micmac, Métis or Inuit)
☐ East Asian (Chinese, Japanese, Korean, Taiwanese, Mongolian, Pacific Islander, etc.
☐ South Asian (Bangladeshi, East Indian, Pakistani, Sri Lankan, etc.)

☐ Southeast Asian (Cambodian, Filipino, Vietnamese, etc.)
☐ Arab/West Asian (e.g., Armenian, Egyptian, Iranian, Lebanese, Moroccan)
☐ Hispanic, Latin American
☐ Other – Specify: ____
☐ Don't know
☐ Refused

13. Which of the following best describes your current living arrangement?

☐ Living with a partner or spouse
☐ Living alone
☐ Living with children or grandchildren
☐ Living with other relatives
☐ Living with non-relatives
☐ Other– specify: __________________________________

14. Do you have any health conditions that are of concern?

☐ Yes
☐ No
☐ Refused
☐ Don't know
☐ Other– specify: __________________________________

15. Do you consider yourself to have a disability or chronic illness?

☐ Yes
☐ No
☐ Refused
☐ Don't know
☐ Other– specify: __________________________________

16. If you consider yourself to have a disability or chronic illness, which of the following is an area in which you have difficulties (check all that apply):

☐ Sensory (hearing, vision/sight, smell, etc.)
☐ Mobility (walking, bodily movement or pain, etc.)
☐ Intellectual (memory, thought, etc.)
☐ Refused
☐ Don't know
☐ Not applicable
☐ Other– specify: __________________________________

17. Are you currently employed and receiving income? Full time or Part time?
☐ Yes- Full time______ Part time______
☐ No
☐ Other– specify: __________________________________

18. Are you enrolled in an educational institution?

☐ Yes- Full time______ Part time______
☐ No
☐ Other– specify: ___________________________________

19. What is your household income?
☐ Under $10,000
☐ $10000-$19,999
☐ $20,000-$29,999
☐ $30,000-$39,999
☐ $40,000-$49,999
☐ $50,000-$59,999
☐ $60,000-$69,999
☐ $70,000-$79,999
☐ $80,000-$89,999
☐ $90,000-$99,999
☐ $100,000-$124,999
☐ $125,999-$149,999
☐ $150,000 and above
☐ Prefer not to answer

20. Who pays for private home care services?
☐ The household
☐ Myself (caregiver)
☐ The individual being cared for?
☐ Other– specify:
☐ Not applicable

21. Which caregiving duties do you engage in?
☐ **Assisting with personal care:** bathing and grooming, dressing, toileting, and exercise
☐ **Basic food preparation:** preparing meals
☐ **Medical care**: overseeing medication and prescriptions usage, appointment scheduling, going to appointments
☐ **Mobility assistance:** Helping to get in and out of a wheelchair, car or shower
☐ **Transportation to and from places**
☐ Personal and Emotional support- companionship (talking too, reading too)

22. How many hours a day do you spend on the caregiving duties described in the previous question?
☐ 0-2
☐ 2-4
☐ 4-6
☐ 6-8

☐ 8-10
☐ 10-12
☐ 12-14
☐ more than 14

23. What other duties are you responsible for at home? And # hours per day?

☐ Cooking
☐ Cleaning
☐ Grocery shopping
☐ Laundry
☐ Looking after children
☐ Looking after grandchildren
☐ Looking after pets
☐ Other- Specify________

Appendix B

Care Dependency Scale

Answered on behalf of the caregiver. Please select one of the answers, by highlighting the right bullet choice.

Caregiver’s Name: ____________________

A. Eating and drinking
The extent to which the patient is able to satisfy his/her need for food and drink:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

B. Continence
The extent to which the patient is able to control the discharge of urine and faeces voluntarily:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

C. Body posture
The extent to which the patient is able to adopt a position appropriate to a certain activity:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

D. Mobility
The extent to which the patient is able to move about unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others

- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

E. Day/night pattern
The extent to which the patient can maintain an appropriate day/night cycle unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

F. Getting dressed and undressed
The extent to which the patient is able to get dressed and undressed unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from other

G. Body temperature
The extent to which the patient is able to protect his/her body temperature against external influences unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from other

H. Hygiene
The extent to which the patient is able to to take care of his/her personal hygiene unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from other

I. Avoidance of danger
The extent to which the patient is able to assure his/her own safety unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

J. Communication
The extent to which the patient is able to communicate:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

K. Contact with others
The extent to which the patient is able to appropriately make, maintain and end social contacts:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

L. Sense of standards and values
The extent to which the patient is able to observe rules by him/herself:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

M. Daily activities
The extent to which the patient is able to structure daily activities within the facility unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

N. Recreational activities

The extent to which the patient is able to participate in activities outside the facility unaided:

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

O. Learning ability

The extent to which the patient is able to acquire knowledge and/or skills and/or to retain that which was previously learned unaided

- Patient is completely dependent on care from others
- Patient is to a great extent dependent on care from others
- Patient is partially dependent on care from others
- Patient is only to a limited extent dependent on care from others
- Patient is almost independent on care from others

Thank you for completing the scale