Transitions into Personal Care Homes: Policy, Practice, and Lived Experience

by

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Abstract

Family caregivers play a crucial part in assisting older adults as they transition into long-term care facilities, or Personal Care Homes (PCHs) as they are known in Manitoba. However, there is limited research on experiences family caregivers have with the health care system throughout this process. This study, through thematic analysis of secondary qualitative data, explored the experiences of 22 family caregivers as they transitioned an older adult across the continuum of care in Winnipeg, Manitoba. Particular attention was paid to the way in which caregivers were accorded choice and control within their interactions with the health care system. Caregiver experiences were juxtaposed with thematic and discourse analysis of secondary qualitative data including 9 service provider perspectives of navigating experiences, and public presentations of how the system is portrayed through governmental and regional health websites. The findings of this study are organized into three phases (pre-panel, panel, and post-placement) with associated sub-themes describing different aspects of structural burden throughout the transition process. Care responsibilities and requirements performed by family caregivers transcend typical assumptions of care provision, beyond social and medical care to often extensive and invisible administrative and information work. This thesis highlights the structural burden that accompanies providing care for older adults in the community, and in particular how this burden can further influence the need to initiate the transition process.

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This thesis was brought to you by the letter ‘C’ for coffee.

Dedication

To Linda: The quintessential caregiver

Words cannot express the gratitude I have for everything you have done.

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Chapter 1: Introduction

As of 2015, the proportion of older adults (those aged 65 and over) in Canada outnumbered children (aged 15 and under) for the first time (Statistics Canada, 2015). The number of older adults is expected to almost double in the next twenty years; it has been estimated that by the year 2036, one in every four Canadians will be over 65 (Statistics Canada, 2014). This has been attributed to decreases in fertility rates over time, developments in medicine, public health policy as well as social determinants resulting in higher life expectancies (Armstrong & Daly, 2017; Doupe et al, 2011). For some older adults, this extended longevity of life has come with the burden of an increase in chronic conditions and comorbidities. This has resulted in a significant number of older adults who, despite receiving extensive care in the community, can no longer safely reside in their own homes and require the added level of medical care available to them in long-term care facilities (Garner et al., 2018), which are known as personal care homes[1] (PCH) in Manitoba. As such, it has been anticipated that more long-term care beds will be needed in the future (Armstrong & Daly, 2017).

Usage rates of long-term care beds have declined in recent decades, this has been attributed to shorter average lengths of stay of residents (Chateau et al., 2012), as a "growing number of residents [who] die within six months of entering a [long-term care] home" (Armstrong & Daly, 2017, pg. 15). While the number of long term care beds has remained relatively stable since 2004 (CIHI, 2011) there is a greater emphasis on utilizing all non-facility options in care before admission can be approved (such as home care and supportive housing), as well as increased eligibility criteria for facilities (Funk, 2016; Canadian Healthcare Association,

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[1] Also known as nursing homes, residential facilities, retirement homes, or long-term care homes

2009; CIHI, 2011; Chateau et al., 2012). As a result, the population of individuals residing in long-term care is becoming more complex, as they are entering long-term care with “advanced frailty” (Armstrong & Daly, 2017, pg. 15), and “only when they are in the greatest need, often frailer and with higher levels of cognitive impairment than historical norms” (Funk, 2016, pg. 89). Conversely, this means that older adults are remaining in community receiving varying levels of formal and informal support with higher care needs and levels of frailty and cognitive impairment than before.

Long-term care should exist in the context of a continuum of care, ideally it would be located within a system that guides and tracks individuals over time through a comprehensive array of health and social services spanning many levels of care (Evashwick, 1989a; Havens, 1995). Continuums of care, in actuality, are comprised of many care systems with varying levels of integration that exist under the umbrella term of a continuum. The full continuum of care should include “extended care, acute hospital care, ambulatory care, home care, outreach, wellness, and housing” (Evashwick, 1989b, pg. 36). While the full continuum of care is quite extensive, for the purposes of this thesis, when I refer to continuum of care, I am referring specifically to the continuum of housing care. Manitoba’s continuum of housing care is comprised of community-based services (home care services, supportive housing) and institutional care (personal care homes, chronic care facilities) (Doupe et al., 2011, pg. 20). This involves programs, services, and housing facilities that are in part publicly funded through the health care system. Predicting transitions along Manitoba’s continuum of care is difficult, as exit and entry criteria to the differing aspects of the continuum are unclear and not uniformly enforced (Doupe et al., 2011).

Family caregivers are often tasked with assisting older adults in system navigation. (Funk, Dansereau and Novek, 2017). This remains true for transitioning an older adult through the health care system along the continuum of care and into a PCH. They take on this role due to filial responsibility and expectations due to physical and mental declines in older adults, as this population of older adults is increasingly becoming frailer and more dependent, with more complex care needs and higher levels of cognitive impairment at admission than historical norms (Chateau et al., 2012; Funk, 2016). Often families do not have a choice about whether to provide care for older adults. This becomes especially salient when health care systems offload care responsibilities onto informal caregivers. As an example. homecare services are not guaranteed services, as they are considered an "extended health service" under *The Canada Health Act* and informal or family caregivers are relied up to fill these gaps in formal healthcare services (Auditor General of Manitoba, 2015).

For families, transitioning an older adult into a PCH is an emotional time filled with many tough decisions that often must be made quickly. Additionally, there is public rhetoric and discourse around transitions into long term care that emphasize both importance and existence of choice and autonomy over the transition process. Despite this, the process of transitioning an older adult along the continuum of care and into a PCH is often unclear with inconsistent communication. There may be contradictions between expectations on how the process is supposed to work and how the transition is experienced. As such, a more in-depth examination into the experience of the transition process is a critical step in health planning for aging societies.

The emphasis in health research on transitions tends to focus primarily on moves between hospital and home (Gozalo et al., 2011). Comparatively, fewer studies have examined the experiences of family caregivers as they assist older adults across the care continuum more broadly, and in particular, transition into long-term care. Public perception and representation of choice throughout the transition process, should take into consideration the "socially constructed nature of decision making" (Collyer et al., 2015, pg. 687). Investigating the forms of recognized and assumed transitions into long-term care can help expose the inconsistencies between standard expectations and lived experience (Grenier, 2012). Caregivers make choices and develop strategies when interacting with the health care system. A sociological interrogation into the way in which caregivers assume the transition process works, and the choices they will have throughout that process, is imperative to understanding the neoliberal discourses that permeate decision-making in the health care system.

In this thesis I examine the experiences of family caregivers as they assist older adults along the continuum of care, resulting in (most cases) eventual personal care home placement within Winnipeg, Manitoba. Havens (1995) emphasizes that long-term care be "conceptualized as including community care and informal care, as well as institutional long-term care" (pg. 246). As such, experiences with all aspects of the transition (receiving home care at home to post-placement) were examined. I paid particular attention to expressions and experiences of choice and control (or lack of) family caregivers had throughout the process. Caregiver choices are both structured and influenced by broader social structures and contexts, but "there is always some room for individual agency" (Collyer et al., 2015, pg. 689). Making this a particularly salient area for sociological theorising. Caregiver experiences were juxtaposed with service provider perspectives of the transition experience, as well as publicly available documents, to understand how this process is presented and understood formally. This allowed me to interrogate the intersection between policy, practice, and lived experience.

This research involved qualitative secondary data analysis utilizing two data sets from a Manitoba Health Research Council (Research Manitoba) funded project: one data set includes family caregivers' experiences of system navigation broadly and one data set includes service providers' perspectives about families' navigational experiences[2]. My research addressed how family caregiver experiences of PCH transitions compared/contrasted against professional and policy/public expressions of the process, to provide a detailed and nuanced assessment of system navigation experiences throughout the transition into PCH. As health policies are not publicly available in the province of Manitoba, policy expressions were gleaned from service provider perspectives and representations of the process, as well as a review of publicly available information on the transition process for entrance into a PCH.

Primarily research on transitions into long-term care highlight the emotions involved, namely guilt, shame, and failure felt by family caregivers when a family member is placed in long-term care (Reuss, Dupuis, and Whitfield, 2005). However, little research focuses on the experience of the transition process itself, particularly the system navigation that is involved. Research is also lacking in the area of accessing long term care and the system based processes and procedures family caregivers must go through. There is very little research about the experience of transitioning an older adult into a personal care home, particularly in a Manitoba context.

This research contributes to this area of knowledge by helping to understand how family caregivers experiences are affected by the health care system when transitioning an older adult into a personal care home. It does so by examining the intersection of practice and lived experience, through a juxtaposition of how service providers portray and interpret family

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[2] The original project and subsequent data sets were approved by the Psychology/Sociology Research Ethics Board for Dr. Laura Funk

caregivers' experiences with the transition process, with family caregiver portrayals of their experiences. Caregivers, through their daily lives and interactions with the health care system, "act unconsciously according tot heir habitus and sometimes make choices and develop strategies as they engage with various social fields, gathering and deploying forms of capital" (Collyer et al., 2015, pg. 689). I will be therefore be investigating the way in which caregivers exercise agency through the social system and structures in place that organize and reinforce the health care system. While some service providers were more reflexive than others, this should not discount experiences as rhetoric, as service provider accounts of family caregiver experiences can be infused with neoliberalizing trends and discourses. Caregivers often spoke of the way in which working within the confines of policy affected their ability to assist caregivers and older adults transition throughout the process. Careful attention was given to the discourses used (what was said and not said) regarding the goals of service provider positions in helping family caregivers navigate within the broader context of health and social care service delivery. The goals of this study were to: i) to better understand the experiences of family caregivers as they transition an older adult into a PCH (especially in regard to their level of choice and control), ii) to better understand service provider interpretations of caregiver experiences throughout this transition, and iii) to understand what kind of publicly available information is available to inform caregivers about this transition. The ultimate applied goal of this research is to improve the transition experience for families and older adults.

I utilized critical gerontological theory and a political economy of healthcare outlook to inform the analysis and interpretation of the data. Critical gerontology examines the intersection of the lives of older adults and the social structures they encounter and navigate (Estes & Phillipson, 2007). A critical gerontological approach stresses that the issues families are having with the transition process are not a failure of the families themselves, but a failure of the health care system to adequately plan for an aging society. This includes a health care system which increasingly pushes the responsibility of caring for older adults back on to families, due to a manufactured concern over the rising health care costs of older adults, individualizing the 'problem' of aging. It also critiques the biomedical approach to aging that frames it as a "biological, physiological [state of[cognitive decline and decay" Estes, 1999, pg. 136) to be treated. A political economy of healthcare outlook involves similar ideas, in particular it examines who benefits when the costs of caring for older adults is shifted from the public sphere (hospital, long-term care) to the private (home) (Armstrong, Armstrong & Coburn, 2001). Armstrong and Armstrong (2016a) contend: "governments avoid making firm commitments to filling the gaps left by reductions in nursing home availability. Too often, the reality is that aging in place is more about limiting the responsibilities of government than about fully meeting the care needs of seniors" (pg. 2). The political economy of healthcare perspective explores the informal labour and work that family caregivers provide, while acknowledging the way in which the health care system employs neo-liberal, individualizing, imperatives for reducing the costs of care.

Utilizing these two theoretical approaches is imperative to a critical and in-depth understanding the experiences of caregivers while providing care for older adults. As they help highlight the the often-hidden cultural ageism and familialism ingrained into health care systems. This is especially pertinent as the growing number of 'aging in place' strategies have consequences for not only family caregivers and older adults throughout the transition process, but the health care system itself. This research offers suggestion areas to stakeholders to allow for smoother transition processes for Manitobans.

This thesis is comprised of eight chapters, including this introduction. In chapter two, I introduce the two theoretical perspectives that informed my work: critical gerontology and political economy of healthcare. The third chapter will provide a more in-depth overview of the literature around caregiver experiences when transitioning older adults in health care settings, as well as providing context for the continuum of care in Manitoba. In chapter four I outline the multi-layered research design as well as my methodological approaches and choices. I present my findings in three phases through chapters five through seven: chapter five is formed through experiences throughout the pre-panel phase, chapter six involves experiences with the panel/transition phase, and chapter seven the post-placement phases examines experiences after an older adult has moved into the care home. Sub-themes are identified amongst each findings chapter. This study concludes with chapter eight, in which I summarize my findings, discuss potential contributions of this project, and final conclusions.

Chapter 2: Theoretical Framework

This chapter sets out the theoretical underpinnings of the analyses of my findings. It will discuss the two theoretical perspectives that informed my thesis: a critical gerontological perspective, as well as a political economy of healthcare perspective.

Research on transitions tend to be interdisciplinary in nature, as this topic crosses disciplinary boundaries it can, at times, be merely descriptive in nature, offering no extension to broader sociological implications. Existing literature on caregiver experiences with transitions tends to utilize a grounded theory approach (Giosa et al., 2014; Ryan, McKenna & Slevin, 2012; Sussman and Dupuis, 2012; Ryan and McKenna, 2013; Ryan and Scullion, 2000), or is a-theoretical in nature (Dellasega and Mastrian, 1995; Rodgers, 1997; Nolan and Dellasega, 2000). Additionally, research on the transition process into long-term care tends to focus particularly on the decision process, resulting in a description of the emotions during this time such as "guilt, sadness, uncertainty, and confusion" (Sussman & Dupuis, 2012, pg. 396). Rarely does research examine caregiver experiences with the process itself. As such, a sociological perspective offers a way to view transitions through strong grounding theories to provide insights into broader sociological contexts and interpretations linking individual experiences to broader structures of care. I begin this chapter by introducing both the critical gerontological perspective and the political health care perspective broadly. I will then describe how these theories inform my research and analysis on caregiver interactions with health care transitions and interactions.

CRITICAL GERONTOLOGY

Critical gerontology has evolved from the incorporation of many different theoretical perspectives including, but not limited to conflict theory, feminist theory, and political theory through an intersectional lens to examine "concerns of social inequalities and social justice"

(Estes & Phillpson, 2007, pg. 331). It provides a multidisciplinary lens in which to examine "social creation of the dependent status of the elderly, and the management of that dependency through public policies and health and social services" (Minkler, 1999, pg. 1). Utilizing a conflict perspective, critical gerontology examines how structural inequalities have "significant consequences for the trajectory of the life course and life chances of individuals in old age" (Estes & Phillipson, 2007, pg. 331). It shows how old age and aging are constructed and problematized in society, as a problem to be solved. The dependent older adult is thus a social construction that occurs "through public policies and health and social services" (Minkler, 1999, pg.1) A critical perspective posits that we are often oblivious to how much social structures constrain older adults in their everyday lives and cautions against individualizing inequalities by "deflect[ing] attention away from the social, economic and political forces that produce them" (Estes & Phillipson, 2007, pg. 335).

Critical gerontology allows us to challenge taken for granted policies and processes, for example the way 'aging in place' policies have been implemented as a way to maximize user choice when in fact they result in "the devolution of federal responsibility to ever lower levels of government and to the individual and family as well as the increasing informalization of care" (Estes & Phillipson, 2007, pg. 333). This theoretical perspective is especially salient when examining health system processes. As the aging process has been constructed as constituting "biological, physiological, and cognitive decline and decay" (Estes, 1999, pg. 136). The medico-centric health care system, which focuses on "individual pathology and medical interventions" portrays old age as a disease to be treated (Estes, 1999, pg. 137). However, the current biomedical health care system, founded on acute care approaches privileges the medical professionals within the health care system that focus on medical based forms of management and control, and away from social and environmental factors (Funk, 2016).

Critical gerontology, when applied to social policy and aging, pays particular attention to the way power through organizational and institutional structures and policies affect the everyday lives of people (Estes & Phillipson, 2007). In this instance, the way in which the responsibility for caring for older adults is shifted more heavily on family caregivers and away from governmental supports. Critical gerontology also incorporates aspects of moral economy, in that it "makes explicit the often implicit cultural beliefs and values underlying societal policies and practices affecting the old" (Minkler, 1999, pg. 2). Some of the ways in which these structures and policies affect people include proposals of privatization, diminishing coverage, increased market economics, and increased emphasis on personal responsibility for health as well as familial expectations. Concepts which are present in the current neoliberal emphasis on personal responsibility and health consumption at the individual level (Fries, 2019).

Through my analysis of family caregiver experiences as well as service provider perspectives, I examine the ways in which each participant group described the system procedures that are involved in the transition process into PCH. In particular how caregivers interacted with and were affected by these processes and procedures. Estes (1999) contends that the "community long-term care system is more than a system for distributing services; it is a system of social relationships that reflects and bolsters the power inequities between experts and lay persons" (pg. 138). Throughout my analysis I paid particular attention to the way in which power inequalities (between caregivers and service providers) and responsibility of care (between the system and caregiver) was understood and experienced.

Critical gerontology acknowledges that the rhetoric of apocalyptic demography has important social policy implications for older adults, specifically the mentality that: “social policy reform is guided by the idea that deep cuts have to be made to accommodate the increasing numbers and percentages of seniors in our population,” (Chappell et al., 2003, 24). A common discourse with regards to aging and health care costs is that the rising older population will bankrupt the healthcare system, this has sometimes been referred to as the ‘grey wave’ or the ‘grey tsunami’. However, aging has been found to only be a limited or modest driver of health care costs: “population aging contributed an annual average growth of only 0.9%” (CIHI, 2018, pg. 25). CIHI (2018) states that this number has not significantly changed over the past decade. Regardless, these concerns are often “raised in the context of austerity measures, attacks on taxation, support for profits and commercial sector involvement in government services, and the promotion of the individual or family responsibility for the payment and provision of care” (Armstrong & Daly, 2017, 15). Future projections of health care costs suggest that, while being a modest cost driver, the effects of aging will happen slowly and steadily (CIHI, 2018). Regarding apocalyptic demography, Northcott (1994) states “the crisis definition of population aging has become widely promulgated in order to “sell” the public generally and seniors particularly on the need to “sacrifice” regarding public spending on programs for seniors…either tax increases or program spending cuts…” (pg. 195). Through the rhetoric of apocalyptic demography and successful aging, older adults are thus held morally responsible for maintaining their own health, while caregivers are responsible for assisting them.

It has been argued that it is not demographics (the rising number of older adults) that are driving health care costs, but conflicting social priorities that are well within our control, including the rising costs of hospitals, drugs, and physicians (Barer et al., 1995; CIHI, 2018).

These three main drivers of health care costs account for the largest share of health spending at 60% combined (CIHI, 2018). McDaniel (1987) asserts that the population aging paradigm promotes the notion that the problem lies with inevitable demographic change rather than health care policies themselves. However, the population aging increases health care costs by less than one percent per year (Rachilis, 2011; CIHI, 2018). McDaniel (1987) further states that inadequacies of and inappropriate use of the health care system are a considerable driver of health care costs.

CIHI (2018) states the national expenditure trends for health care drivers are expected to grow, with drugs accounting for 4.2%, spending on hospitals accounting for 4.0%, and physician spending forecast at 3.1%. Despite this, the rising costs of the aging population continue to be at the centre of the health care debate surrounding health care restructuring, providing rhetoric for both the cause of the restructuring (i.e. increasing demand), and those most affected by it (McDaniel, 1997). This is not due to utilization choices made by older adults, but on care needs being treated inappropriately in facilities that escalate health care costs (McDaniel, 1987), in particular "costly and high-tech institutions, such as hospitals, under the professional control of physicians" (Fries, 2019, pg. 7). Individuals are being treated and placed in hospitals as there are insufficient community supports in place to transition them home, coupled with an insufficient amount of long-term care beds. It is anticipated that the need for complex nursing care is rising and there are not enough nursing home beds to meet the demands of the oldest old (Harrington, 1999). This is not to be blamed on demography, but on a health care system that was originally organized based on acute care populations and priorities and has not adapted to, or kept pace with, demographic changes (Havens, 1995).

POLITICAL ECONOMY OF HEALTH CARE

Critical gerontology has its origins in the political economy perspective, and as such these two perspectives are intrinsically linked. Armstrong, Armstrong & Coburn (2011) contend that health care is “not only part of markets, but part of the household sphere” (pg. 1). However, underfunding of medicare, as well as cutbacks to health funding by the federal government are resulting in an over-reliance on informal caregivers. The costs of providing care are thus shifted from the public health care system to the private household (Armstrong et al., 2011). As such, the political economy perspective explores the informal labour and work that family caregivers provide, while taking into account “the neo-liberal governmental logics that aim to reduce the costs of care” (Barken, Daly & Armstrong, 2016, 325). Armstrong and colleagues contend that at times, crises are manufactured by “governments and their media and private-sector supporters” (2011, pg. 4), to legitimize cuts to programs and services within the health care system, effectively hollowing it out.

The political economy of health care as outlined by Armstrong and Armstrong (2016a) proposes that, “governments avoid making firm commitments to filling the gaps left by reductions in nursing home availability. Too often, the reality is that aging in place is more about limiting the responsibilities of government than about fully meeting the care needs of seniors” (pg. 2). Aging in place policies significantly shift care work onto families; this is often obscured behind the rhetoric of choice for the older adult. Collyer and colleagues (2015) contend that “patient choice has become a key goal of health care planning” (pg. 686). However, this presupposes that older adults are able to make rational, and informed decisions. Often hidden in research is the work and decision making that caregivers perform when caring for an older adult. Additionally, choices are often shaped “by the decisions and practices of [the health care systems] ‘gatekeepers’: the health care providers, managers, administrators, policy-makers and significant others in the institutions and organizations of both private and public healthcare" (Collyer, 2015, pg. 693). Choice in health care decision making thus constructed through the way in which economic, political, social, and cultural power interact and best suit the system.

Missing from transition research on long-term care policy is the examination of system navigation on behalf of older adults, in particular the process of transitioning older adults along the healthcare continuum. My research therefore expands the purview of critical gerontological research and political economic perspectives by juxtaposing lived experiences of family caregiver experiences of the transition against service provider policy expressions.

In examining the experience of transitioning an older adult into long-term care, critical gerontology strives to distinguish between the choices that people are told are available to them, and what they express as their own needs (Estes & Phillipson, 2007). My analysis examines the experience of the transition process, particularly what family caregivers convey about how the system heard and responded to the needs of both themselves and their family member. In particular, I looked at the amount of choice and control family caregivers expressed that they had throughout the transition process. Investigating the forms of recognized and assumed transitions in later life can help expose inconsistencies between standard expectations and lived experience (Grenier, 2012). Applying these two perspectives to my analysis offer a way to examine caregiver experiences, while understanding the underlying nature and complexities of priorities with the health care system. This helped to bring forward the often-hidden cultural ageism and familialism ingrained into health care systems.

In this chapter I discussed the two theoretical perspectives that have guided my analyses: critical gerontology, and political economy of health care. In Chapter 3, I introduce background and context on Manitoba's continuum of housing care, as well as literature around caregiver experiences while guiding older adults through with health care transitions.

Chapter 3: Context and Literature Review

This chapter begins by providing context for the Canadian health care system, in particular the location of home care and residential care within it. It then details the concept of continuums of care, focusing specifically on the continuum in Manitoba. The intent of which is to provide context for those who may be unfamiliar with how the system is organized. Following this, I provide a review of the academic literature on transitions into long-term care, as well as choice and how this concept is understood regarding long-term care.

HOME CARE, LONG-TERM CARE AND THE CANADIAN HEALTH CARE SYSTEM

The Canadian health care system is a tax-funded single-payer arrangement founded on five key principles as outlined in the 1984 *Canada Health Act*: public administration, universality, comprehensiveness, accessibility, and portability. Funds are collected through general taxation and allocated to the provinces and territories to be used at their discretion; it is a system "*controlled* by the provinces but *coordinated* by the federal government, with the province's consent" (Fierlbeck, 2011, 18). This has resulted in regional variation in the health care services provided to individuals. The Canadian health care system is generally understood as following a universal model, however, in fact, the Medicare system covers mainly primary and emergent care (hospital care), while other facets of health care are not covered.

In particular, home care and residential care for older adults is excluded from Canada's Medicare program these are considered not medically necessary. Rather, "nursing home intermediate care, adult residential care, home care, and ambulatory care services" (Rachilis, 2011, pg. 108), are deemed 'extended health care services'. This reinforces the notion that aspects of continuing care are considered "optional extra[s] for the provinces" (Rachlis, 2011, 108). This has led to varying forms in funding and delivery in this sector between provinces (Wister and McPherson, 2011; Funk 2016). This has also meant that the principles of the Canada Health Act are not applied to the long term care needs for older adults.

With an emphasis on fiscal responsibility, efforts have been made to shift the crux of care from hospital settings to the community, where possible. Hospitals, “have cut back their services, releasing patients quicker and sicker” (Armstrong & Armstrong, 2016). This shifts the emphasis of care off of the public health care system into the private sphere (the home). When care needs can no longer be managed in the community, many older adults will require institutionalization into a long-term care facility to have their needs appropriately met. The system, however, emphasizes utilizing all non-facility options in care provision before admission into a facility can be approved, as well as increased eligibility of facilities (Funk, 2016; Canadian Healthcare Association, 2009; CIHI, 2011; Chateau et al., 2012). As a result, the population of individuals residing in long-term care is becoming more complex, as they are entering long-term care with “advanced frailty” (Armstrong & Daly, 2017, pg. 15), and “only when they are in the greatest need” (Funk, 2016, pg. 89). This has resulted in institutionalization often being viewed by older adults and their families as a last resort.

The consequences of leaving older adults in the community too long can be quite severe, resulting in: caregiver burnout, additional out of pocket expenses for caregiving, a congested waiting list for long-term care, as well as potential safety concerns for the older adults (Ryan and Scullion, 2000; Giosa et al., 2014; Sussman and Dupuis, 2012; Keefe and Fancey, 2000; Reuss et al., 2005). However, the consequences of institutionalizing an older adult too early can be social isolation, decline in functioning, and depression in the older adult (Dellesaga & Mastrian, 1995; Adekpedjou et al., 2018; Nord, 2016). Knowing the right time to initiate this transition is difficult for both family caregivers, (who weigh their wants and needs with that of the older adult) and the system (that determines through gatekeeping techniques whether an individual is eligible). At its core, the goal of Home Care Programs is to keep older adults in the community for as long as it is safe, however, with long wait times and increased eligibility criteria for long-term care facilities, there is a greater risk for adverse health incidents that precipitate hospitalization for older adult waiting for a bed offer, and greater burden on caregivers attempting to meet care needs in the community.

CONTINUUMS OF CARE

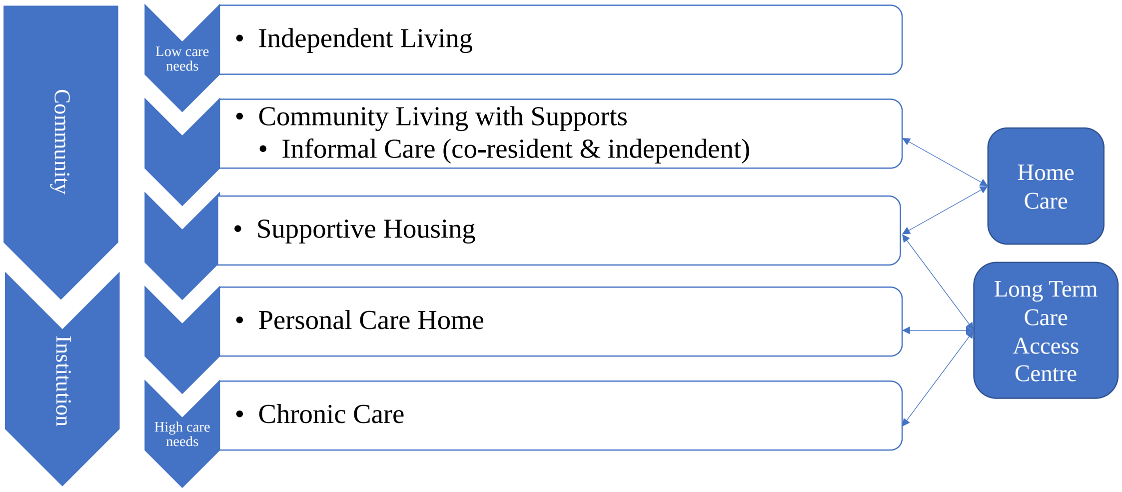
The concept of a continuum of care involves integrated systems that are intended to track individuals over time through a multitude of programs and services, the intent of which is to better meet community needs, eradicate redundancies, and increase efficiencies (Evashwick, 1989a; Banerjee, 2007). The essence of such a concept is to provide "good patient care" (Evashwick, 1989b, pg. 36). However, rarely are continuums this streamlined, as they are typically a conglomerate of multiple systems and services under the umbrella term of a continuum.

Continuums of care are organized so that ideally, individuals transition across the care continuum as their care needs change. However, this assumes a linear care trajectory which is not typically the case. Research shows that care trajectories are often unpredictable and non-linear (Van den Block et al., 2015; Jungers, 2010; Gozalo et al., 2011). This is also made difficult with siloed health care systems with inconsistent communication and exit and entry criteria. The health care system as it is currently understood, is a "highly sophisticated but fragmented collection of service providers" (Evashwick, 1989b), pg. 36). Evanashwick (1989b) contends the rationale for creating a continuum of care is that it is: "(1) appropriate for patients' needs, (2) demanded by today's consumers – individuals and families as well as employers and payers, and (3) a cost-effective way of maximizing use of health care resources" (pg. 36). However, these rationalizations hide the distinct neoliberal influence that privileges the pathogenic health care system. Due to the medical dominance in the biomedical health care system, patients' needs have been artificially defined as those met by medical professionals. Continuums have been presented as better for allowing choice while meeting needs, however this masks the trend toward "market-oriented product development" (Evanshwick, 1989b, pg. 37). Providing choice is therefore is often a catalyst for privatization within health care. The provision of extensive choices can be onerous and unnecessary if the quality of health care service people receive is high enough (Collyer et al., 2015). Health care systems that have been siloed, providing care options in parallel of each other, can result in "patient referrals [going] out of the organization, leaving internal resources underused" (Evanshwick, 1989b, pg. 37). Underused resources, in an attempt to attune to fiscal responsibility, result in funding being reduced, and a hollowed out program.

While patient care is the main priority for the health care system, there is also a system emphasis on fiscal responsibility and health care utilization management. Moreover, continuums on paper are purportedly organized so that individuals can transition up to higher levels of care or down to lower levels of care as their care needs change; individuals in practice tend to require an increase in care along the care continuum rather than a decrease. Reed and colleagues (2003) refer to concept of 'the escalator of care': "once an older person has taken the first step on to the escalator, by accessing services or entering a care facility, they find themselves being moved to increasingly supportive facilities, with no option of a reduction in the level of support they receive, only intermittent increases" (pg. 227). How programs and services are organized and integrated can greatly affect the way in which older adults interact with and are affected by the system. The rationale for a continuum of care, states Evashwick (1989b) is that it "it is appropriate for patients' needs, demanded by today's consumers, an organized way of maximizing use of healthcare resources, and cost-effective for providers, patients, and payers" (pg. 36). However, the utopian view of care continuums is rarely reflected in practise. Despite this, there is "a consensus of experts in the field that long term care is a continuum" (Armstrong, 2016c).

Manitoba's continuum of care is comprised of both community based (independent living, community living with supports and supportive housing) and institutional living (personal care homes, chronic care facilities). Based off of publicly available information, through Manitoba Centre for Health Policy reports (Chateau et al., 2012; Doupe et al., 2011; Doupe et al., 2016), provincial and regional health websites, and my own knowledge of Manitoba's health care system based off research I have done in the area, I created *Figure 1* as a way to visualize Manitoba's continuum of care.

Figure 1. Manitoba's Continuum of Care



Within independent living, older adults are functioning independently from the health care system. They may interact with their general practitioner or receive other health care services, but they require little to no assistance from the publicly funded health care system to remain at home. Community living with supports entails older adults either living independently or are a co-resident with their caregiver. They receive varying forms of informal care from their family and friends but have accessed Home Care services to assist them with their care or daily needs. Supportive housing is a form of publicly subsidized housing intended to provide basic levels of care provision to older adults and reduce long-term care admission to only those with the most need. In addition to the basic care package included in supportive housing, individuals are able to receive home care services. Admission to supportive housing is maintained through paneling process of the Long-Term Care Access Centre (LTCAC). Personal care homes are a publicly funded form of housing that involves access to 24/7 unscheduled care and support from professional and non-professional staff. Admission to PCHs is maintained through the paneling process of the LTCAC. Chronic care wards are for those individuals who require too much medical care to remain safely in PCH. Admission to chronic care wards is maintained through the paneling process of the LTCAC.

Manitoba's continuum of housing care involves programs, services, and housing types that span from community to institutions. The gatekeeper to publicly funded forms of housing is the LTCAC. It is the responsibility of the individual regional health authorities (RHA's) to complete the application/admission paperwork for these forms of housing, however, once this is completed, the information is effectively discharged from the RHA to the LTCAC. The LTCAC is responsible for organizing the panel review boards, ensuring the needs of individuals are being appropriately met, and maintaining the waitlists for long-term care programs, (including supportive housing, personal care homes, and chronic care)[3].

In Manitoba, home care is provided “based on assessed need and in consideration of other resources available to the individual including families, community resources and other programs” (Manitoba Health, Seniors and Active Living, n.d.). It can be received in an individual’s home, apartment, an assisted living facility, or supportive housing setting. Home care is not considered a medically necessary insured service, nor is it a guaranteed service (Auditor General, 2015). As a result, individuals must have a “back-up plan” in place in case a home care worker is not able to make an appointment (Auditor General, 2015). Some families choose to avoid the Home Care Program entirely and hire private services to care for their loved ones, as at times there can be a lack of continuity in home care staff members caring for individuals coupled with an abundance of rescheduled or cancelled appointments. Should it be determined that an individual requires too much support to be managed in the community, the Home Care Case Coordinator will start the panel application process.

In Manitoba there also exists a branch of the Home Care Program entitled Self and Family Managed Care (SFMC) that allows either the individual receiving care, or their family member, to accept responsibility for their personal care as managers[4]. As such, they “are responsible for coordinating, managing, and directing the non-professional services they [or their family member] need to continue living at home and in the community”[4]. The Self/Family Manager can choose to either hire an agency or their own staff (but not a family member). Should it be determined that an individual requires too much support to be managed in the

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[3] http://www.wrha.mb.ca/ltc/access.php

[4] http://www.wrha.mb.ca/community/homecare/self-and-family-managed-care.php

community, the family manager should contact their SFMC Home Care Case Coordinator to do an assessment and start the panel application process.

Home care is designed to help people remain safely at home rather than staying in hospital (at a significant cost to the health care system) or transferring to a personal care home; however, with an average wait time of 37 days to receive an assessment (in the WRHA) and an additional 16 days after assessment to receive care (in the WRHA) there can be a significant disconnect in services[5] (Auditor General, 2015, 5).

Paneling Process – Gatekeeping Mechanism

The gatekeeping mechanism for partially publicly funded forms of housing is known as the paneling process, the key component of which is the *Application/Assessment for Long-term Care Placement form.* It is called paneling as the Application/Assessment form is presented to a panel review board, consisting of a physician with experience in geriatrics, and a Home Care Team Manager. Paneling applications can be initiated from either community or hospital[6], but regardless of initial location, paneling is a necessary component of accessing publicly funded forms of housing. From community, typically, the Home Care Case Coordinator[7], (after consultation with the individual, their family, and their health care team), 'makes the case' for placement to the panel review board based on an assessment of the individual. The board consists of "physicians and staff from the Long Term Care Access Centre and Home Care"[8], whose knowledge of the older adult is only second-hand and mediated through existing documentation, such as the *Application/Assessment for Long-term Care Placement form*.

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[5] Between February 2012 and January 2014

[6] This process has recently been changed in an attempt to better help caregivers navigate and avoid PCH placement from hospital, however this practice was common during the time of data collection.

[7] Home Care Case Coordinators typically have some form of professional designation, this can include training in: social work, nursing, physiotherapy or occupational therapy

[8] http://www.wrha.mb.ca/ltc/pch/paneling.php

Alternatively, from hospital, the decision to initiate a panel application is usually made by a doctor or hospital social worker with input from a care team (e.g., including occupational therapist, physiotherapist, and the doctor). Once the decision to panel is made, hospital staff refer the case to a Long Term Care Access Coordinator, who conducts an assessment, and submits the case to the panel review board.

The assessment form has several components: i) the applicant or a representative provides biographical information, ii) the applicant's doctor provides a medical assessment, iii) a nurse completes a functional assessment, care plan, and outlines any factors that affect safe care, iv) typically (but not always) a social worker (home care case coordinator) outlines the reason for application and present living arrangement, any additional information that could be relevant to placement, and calculates the applicant's level of dependency or levels of care.

The level of dependency is determined based on the amount of assistance individuals require to complete activities of daily living (ADLs) in four areas: i) bathing and dressing, ii) assistance with meals including feeding, iii) ambulation/mobility, transfers, and iv) elimination (Doupe et al., 2011). Additionally, an assessment is done based on the need for professional interventions (ex: skin care), and the need for behavioural management (Doupe et al., 2011). This results in a dependency level of 1 (independent or minimal dependence in all 6 areas) to 4 (maximum dependence in four or more areas) (Doupe et al., 2011).

The panel review board may approve, defer, or reject applications to long-term care placement. Their primary function is to act as gatekeepers to long term care placement by determining eligibility and suitability, and ensuing all alternate options are explored. Alternate options would include, for instance, increasing formal supports (home care hours) to keep the individual in the community longer, or, referral into supportive housing.

In 2004, Manitoba Health announced an ‘Aging in Place’ initiative that expanded the continuum of care to introduce Supportive Housing (Doupe et al., 2016). It aims to maintain a home-like setting; part of the basis of appeal is that it is less medically based, which should allow individuals to have more control and independence over their lives than they would a PCH (Doupe et al., 2016; Armstrong & Armstrong, 2016b). However, “these alternatives can mean the loss of life-enriching activities and quality of care” (Armstrong & Armstrong, 2016b, 2). Individuals and their informal or family caregivers must therefore “seek out and arrange all of the various goods and services necessary to supplement the very basic offerings” (Parkland, 2013, pg. 38) of residential care homes while still residing in supportive housing.

Whereas community homecare and institutionalized care tend to be more publicly funded, supportive housing comes at a greater personal cost to individuals, “barring from entry the many seniors with modest or no financial resources” (Armstrong & Armstrong, 2016a). Residents in supportive housing must pay for their own prescriptions, must make their own arrangements to visit physicians, must pay for their own therapies such as OT or PT, and must provide their own specialized supplies and equipment (Doupe et al., 2011). The offloading of costs that occurs in Supportive Housing shifts the responsibility onto individuals and their friends and families. Exit criteria for supportive housing are vague; individuals can transition out of supportive housing if they have cognitively declined to the point that they can no longer safely remain in Supportive Housing, if they exhibit behavior issues, or are incontinent (Doupe et al., 2016). In some instances, transitions from supportive housing to PCH are a matter of necessity and not choice (the supportive housing facility will not allow them to remain). However, most of these conditions could be handled with an appropriate staffing level in place (Doupe et al., 2016).

If an individual requires too much care or support needs to be eligible for supportive housing, they will be typically be paneled for PCH. In most cases, the individual being transitioned into the PCH will be involved with the Home Care Program before entry into PCH. Each PCH has its own average wait times, and families are encouraged to check with each facility they are interested in to determine whether the facility would be appropriate for their loved one. There are 9,697 licensed personal care home beds across Manitoba, the majority of which (5,267 beds) are located within Winnipeg across 39 different PCH facilities (MNU, 2018; Doupe et al., 2016). These facilities tend to operate at or near capacity (Doupe et al., 2011, pg. 12). More than 90% of the occupants in PCH are 75+ years old; the average age is 85 years old (Doupe et al., 2016; MNU, 2018). It is anticipated that this segment of the population will increase by 89.2% from 2007 to 2036 (Doupe et al., 2016). While PCH use rates (days used per 1,000 population) are lower than they once were, they are increasing for those 85+ years old (Doupe et al., 2016).

Manitoba has one of the highest supplies of PCH beds in Canada with 338 beds per 1,000 people 85 and older as compared to other provinces (Doupe et al, 2016, 1). Nonetheless, according to the Manitoba Nurses Union (MNU): “as of late 2017, almost 1,000 Manitobans were waiting for a bed, and of this amount, 47% were waiting in a hospital” (2018, pg. 6). Moreover, it has been projected that Manitobans are going to require between 32% and 53% or 5,100 more bed equivalents (Doupe et al., 2016; MNU, 2018) by the year 2036. Doupe and colleagues (2011) contend the number of people accepted but waiting for admission into a PCH has increased in recent years. It is anticipated that the wait list for PCH admission is going to grow in the upcoming years (Doupe et al., 2011). The emphasis on aging in place, and the “focus on short-term care has meant more work for unpaid family members and friends” (Armstrong &

Armstrong, 2016, pg. 49). Examining the experiences of caregivers throughout the transition process of an older adult into a PCH, noting specifically where structural barriers and policies are causing difficulties will help system planners adapt to the growing population of older adults.

TRANSITIONS AND CHOICE

Research that examines the experiences of family caregivers during the caregiving journey tend to note caregiver feelings regarding the process (Lilly, Robinson, Holzman, & Bottorff, 2012; Purkis & Ceci, 2015; Grenier & Guberman, 2009; Nolan & Dellasega, 2000), the type of care and work required throughout this process (Dalmer, 2018; Dalmer 2017; Hainstock, Cloutier & Penning, 2017; Keefe & Fancey, 2000), the importance of social capital in decision making (Ryan et al., 2012; Ryan and McKenna 2013) the process and consequences of institutionalization (Dellasega and Mastrian, 1995; Sussman and Dupuis, 2012; Rodgers, 1997; Reuss et al., 2005; Ryan & Scullion 2000), changes in caregiving responsibilities after institutionalization (Keefe and Fancey, 2000; Rodgers 1997), the need for transitional supports (Nolan and Dellasega, 2000), and factors that led family caregivers to place older adults in long-term care (Ryan and Scullion, 2000; Lee, Simpson, & Froggatt, 2013; Hicks, Sims-Gould, Byrne, Khan & Stolee, 2012).

During interactions within the health care system, individuals are expected to make informed decisions based on options and information presented to them (Hicks et al, 2012; Ceci and Purkis, 2009). This is typically done through public representations of the system, either through contact with system-based service providers, or publicly available information provided by the system itself. Canada's healthcare system is based in a tradition of "bioethics with an emphasis on individual autonomy in healthcare decision making" (Hicks et al., 2012, pg. 141). As such, individuals are often tasked producing and maintaining their own health through the decisions that they make and actions they take. However, when older adults reach a point where they are no longer able to make decisions for themselves (or ask for caregiver advice and/or support) regarding health care choices, a family caregiver is typically the medical proxy, tasked with making medical decisions on behalf of the older adult.

Research has found that making decisions with/for an older adult "is rarely a straightforward, rational process" (Dellasega & Mastrian, 1995, pg. 125). Conflicting emotions can be a result of the contrast between caregiver wants and needs with that of the older adult they are providing care for. There is often an assumption that there is a linear process in which individuals are presented with particular choices and information (which they are expected to seek out further information) and then make an informed decision (Baxter & Glendenning, 2011; Arksey & Glendenning 2006). This assumption masks the "complexity of healthcare decision making, especially for older people with complex health issues" (Hicks et al., 2012, pg. 140). Current policies in care provision emphasize the importance of 'aging in place', however these types of policies often mask the work that caregivers undertake to maintain older adults in the community (Bookman & Harrington, 2007; Grenier & Guberman, 2009; Dalmer, 2018; Reuss et al, 2005).

Arksey & Glendenning (2006) have discovered that "identifying who makes the decision about entry to residential care is not straightforward. However, the literature about moving to a care home indicates that carers play a key part in both the initial decision to seek long-term care, and in selecting a home" (pg. 170). In their research on palliative care, Funk and colleagues (2009a) found that family caregivers' feelings of support regarding access to care and information was particularly salient. Transitioning an older family member into a long-term care facility can be fraught with difficult and/or conflicting emotions (Rodgers, 1997); for instance, it can be both stressful and traumatic (Dellasega & Mastrian, 1995) as well as involve relief and peace of mind for family carers (Reuss et al., 2005). Emotions such as: “guilt, sadness, loneliness, anger, resentment, a sense of failure, and simultaneous feeling of relief, and peace of mind during the process” (Reuss et al., 2005, pg. 26), as well as “worry, frustration, and uncertainty” (Sussman and Dupuis, 2014), are commonplace. These emotions may be exacerbated or complicated in situations where there is a lack of information for families and pressures to make an early move (Reuss et al., 2005).

For many families, transitioning into a long-term care facility is often referred to as a “last resort” to only be considered once all other options and services have been exhausted. Families often view transitioning an older-adult into a long-term care facility as a sign of caregiving failure (Sussman & Dupuis, 2012), and this experience has been denoted as “one of the most difficult decisions for an elderly person and his/her family to make” (Keefe and Fancey 2000, 235). There are many reasons it has been framed as a “last resort” some of which include: policy emphasis on ageing in place, the North American emphasis on independence, and the rising number of nursing home media scandals circulating in public awareness (Lloyd et al., 2014; Armstrong & Daly, 2017). Despite the negative perception of long-term care facilities, they are increasingly becoming a necessary part of the health care system as there are insufficient supports available to care for complex medical needs in community (Sussman & Dupuis, 2012). Armstrong & Daly (2017) contend “the number of places in care homes has not kept up with the number of people defined as needing care” (pg. 17). As a result, caregivers will be required to provide care for older adults with complex care needs in the future.

Care responsibilities and requirements from family caregivers transcend typical assumptions of care provision, beyond social and medical care to often extensive and invisible administrative and information work (Dalmer, 2018; Funk et al, 2017; Bookman & Harrington, 2017). The efforts to maintain care for older adults in community have had “unintended negative consequences for family members” (Lilly et al, 2012, pg. 103), who provide care. Congruently, admission criteria have become more restrictive, with residents requiring higher “levels of assistance with daily living as well as some medical care” (Armstrong & Daly, 2017, pg. 15) upon admission. As such, transition decisions often must be made on the behalf of older adults by family caregivers. Nord (2016) found that transitions into residential care are typically precipitated by one of two scenarios; “a prolonged period in which increasing frailty is a major motivating factor, or a traumatic crisis” (pg. 60). In both cases the transition is based on necessity that does not always allow for pre-meditation and planning. Often caregivers do not notice the gradually increasing decline of older relatives until a major event occurs. Moreover, since the initial decision about entry into long-term care is often made at a time of crisis, older people may not have influence over the decision to relocate (Arksey & Glendenning, 2006; Nord, 2016).

Research has found that familiarity with the long term care residence is particularly helpful to promote a positive transition experience for older adults and their carers (Ryan & McKenna, 2013). However, often the speed in which the transition needs to occur, or circumstances restrict the potential for pre-placement visits. Research into transitions into long-term care in rural communities found that both family caregivers and older adults have more positive experiences when they feel connected to both the facility, and the social and health professionals in the area, as this allows them access to information and support that might be denied to someone who does not have the same level of social capital (Ryan et al., 2012). Ryan and McKenna (2013) found that familiarity with long-term care facilities and having access “to the local grapevine" (pg. 252), including knowledge of the history of the facility, staff, residents, and community, enhanced the sense of comfort with the transition experience. However, Ryan and colleagues (2012) found that many families are "'working in the dark'…not knowing where to start in the search for a nursing home" (pg. 9).

Nonetheless, choice, or the illusion of choice, has been a prominent fixture in the neoliberal discourse around health and health consumption: "consumer culture and the media support a tendency to view health as a commodity and encourage health-care consumers who want to preserve their investments in the commodity of health" (Segall & Fries, 2011, pg. 11). Choice not only involves choosing to admit a family member into a PCH in the first place, but also other aspects of choice, such as choice in the facility in which they are placed, or choice in timing of transitions (ex: when to enter PCH).

In a time where there is a significant loss of independence and autonomy, retaining agency and 'choice' is important for people, especially as they are forced to relocate to institutionalized care. However, "exercising choice if you have extensive care needs means having options beyond aging in place. Yet constructing long-term care as an attractive option for either the older population or for those who provide care has not been a high priority in most countries" (Armstrong & Daly, 2017, 16). Initiating the placement process is often the responsibility of the caregiver, with ideally some input from the older adult; however, this involves tasks such as looking at homes, asking questions, and completing paperwork. Moreover "the notion of choice suggests that, ideally, a long-term care facility is selected from a range of options that are matched against a list of preferred criteria. In reality, choice can be restricted by the facilities available" (Arksey & Glendinning, 2006, pg. 171). However, information provided to caregivers is often limited, not entirely relevant, or not up to date, and often are given little more than a list of available residential facilities (Arksey & Glendinning, 2006; Ryan & McKenna 2013).

Choice can also be restricted due to socio-economic factors; while the amount paid by the individual residing in a PCH is a means tested daily per diem based on their income (providing no practical barrier to choice), socio-economic advantage has been linked to easier system navigation (Shim, 2010). Funk and colleagues (2017) found: "navigating access to formal systems may be easier for carers with more expertise and confidence, and with more extensive social networks and cultural health capital" (pg. 8). Individuals with modest to no financial resources would be restricted in their ability to reside in Supportive Housing, would lack the ability to purchase private homecare, and could lack the cultural capital required with Self and Family Managed Home Care or system navigation more broadly.

The number of people who require long-term residential care is expected to rise, but the number of care home beds is not expected to keep pace (Armstrong & Armstrong, 2016b). Additionally, Armstrong & Daly (2017) have found in Canada that "only half of those assessed with high or very high needs can count on getting in to a nursing home within a year" (pg. 121) As such, it is expected that many families will encounter a time in which the care needs of a family member in which they care for will surpass their ability to provide that care, and waiting for placement into a long-term care residence may be the only option (Sussman & Dupuis, 2012). An examination of the experiences with the transitory process of entry into personal care homes in Manitoba could greatly benefit family caregivers and the health care system alike, by ideally changing the way the process is conducted.

In sum, Manitoba's continuum of care is comprised of community based and institutional based care, while it might appear to be a streamlined system on paper, it is a conglomerate of individual care systems which runs the risk of inefficiencies and bureaucratic hang-ups, as well as places where people fall between the cracks. As of late 2017, there were almost 1,000 people waiting for a PCH bed, and this number is expected to rise. Informal caregivers are often faced with making critical choices on behalf of older adults regarding transitions; this is a time that is emotional distressing to both the family caregiver and older adult. In most cases the timing of the transition does not allow for premeditation or planning (due to decline or emergency). Research has shown that allowing for choice (ex: when to transition, where to transition to, etc.) on the part of the family caregiver and the older adult is an important aspect of a positive transition but rarely is choice able to be exercised (Lee et al., 2013).

In this chapter I located home care and long term care within the Canadian health care system. I then provided context regarding the concept of a continuum of care, and how this has attempted to be enacted within a Manitoba context. Following this, I reviewed the academic literature on family caregiver experiences during health care transitions involving older adults, with particular attention paid to literature on choice throughout this process. In chapter 4, I outline the research design and methodology I applied in my project.

Chapter 4: Research Design and Methodology

This chapter outlines the research design and methodology that guide this project. I begin by describing the original research project that this thesis stemmed from. Following this, I discuss my multi-layered research design, and how I utilized this in my research approach. I then detail participant descriptions for both the family caregiver and service provider participants. Next, I discuss the analytical strategy I utilized. A statement on trustworthiness concludes the chapter.

ORIGINAL PROJECT

The interview data for my analysis come from a subset of participants from a completed qualitative study of family caregiver system navigation (funded for Dr. L. Funk by MHRC/Research Manitoba). The original project consisted of in-depth, in-person interviews with 32 family caregivers in or near Winnipeg, Manitoba who navigate systems on behalf of older adults (Funk, Dansereau, and Novek, 2017). The research question for the initial project was: how do family carers of older adults experience the work of system navigation? System navigation was defined as accessing any of a wide variety of health and/or social services, supplies, and resources for the older adult, but could also include the work involved in ongoing monitoring and coordination once services were initially accessed.

Interviews were conducted by several research assistants (including myself) between October 2014 and May 2015. Participants were recruited through advertisements, as well as both written (posters in community and seniors' centres, local newspapers, etc.) and verbal communication (radio advertisements). The original study utilized a criterion sampling technique to ensure that all participants fit the scope of research (i.e. had ample experience navigating systems on behalf of an older adult).

The study included up to three iterations of interviews with carer participants, with follow-up interviews occurring approximately six-nine months after the previous interview. Time 3 interviews were only conducted if significant changes had occurred in the system navigation practices of participants, the participants consented, and they had not become bereaved in that time. Seventeen (of 32) participants were interviewed three times, 12 (of 32) participants were interviewed two times, and four (of 32) participants were interviewed only once. The interview guide for the initial interviews (Appendix I) was loosely structured and included open-ended questions to elicit experiences of system navigation of formal services. Individual modifications were made to the subsequent interview guides to elicit deeper understanding, additional examples of system navigation and corresponding emotions and experiences associated with this process.

Additionally, as part of this project, data were also collected through 22 in-person, qualitative interviews[9] with private and non-profit service providers in Winnipeg (Funk & Hounslow, 2019). The research questions for this component of the study were: a) how do service providers act as system navigators for family caregivers to older adults, and how do they interpret their roles? B) from the perspective of these system navigators, what are the root sources of challenges faced by family caregivers in navigating systems, and how can these be ameliorated? And c) from the perspective of system navigators, which groups of family caregivers are most disadvantaged when it comes to system navigation? Service providers included individuals employed with the Winnipeg Regional Health Authority (long-term care system navigators, home care case coordinators, social workers, etc.), employees of non-profit organizations (executive directors, client support coordinators, etc.), and private consultants. A

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[9] Data was collected by myself and one other research assistant

requirement for their participation was that helping family carers with system navigation was a significant part of their role or position. Recruitment for service providers occurred via written communication to managers in the WRHA and non-profit organizations as well as phone calls to private consultants identified through the internet. The service provider participants were asked broad questions (Appendix II) about their role and position, how they assist family caregivers in navigating systems and where they believe families encounter barriers and problems.

THIS THESIS

My analysis utilizes these datasets to investigate a new and different research question that emerged during the initial study but was not specifically explored there. In line with secondary qualitative analysis, I used the "existing data to extend a pre-existing study or undertake new analysis of the data" (Hanson, 2010). Specifically, I asked: how do family experiences of PCH transitions compare to professional and public/policy expressions of the process? This research is focused within the city of Winnipeg, Manitoba. Although the original study was not intended to answer this particular question, transitions of an older adult into a personal care home were described frequently during the interview(s) with family carers. Service providers (formal navigators) also spoke of providing assistance to families who were experiencing this transition, and the structural barriers that at times restricted their ability to fully assist with this process.

Initially, I had intended to focus specifically on the main gatekeeping tool utilized when deciding if PCH placement is appropriate for older adults, namely the paneling process. However, after a cursory look at multiple transcripts, as well as engaging with literature on transitions, it became clear that the transition into PCHs involves many more system interactions than solely the paneling process. In order to fully understand the caregiver experience of transitioning an older adult into a PCH, it was important that I understand the circumstances that led to the decision to panel. Through this I was able to expand my findings to the broader institutional and social structures that influence not only the transition process, but the need to initiation the transition.

Originally, my research design consisted of two phases. The first a multi-layered analysis of the family caregiver subsample utilizing a) a thematic analysis of all selected transcripts; b) a narrative analysis of a subsample of the richest or most theoretically noteworthy transcripts; and c) a paradigmatic comparison of strategically selected cases or exemplars. Following this, I had planned to analyze the service provider transcripts and publicly available information of the transition process using thematic and discourse techniques. However, after expanding my research focus to incorporate the full range of what caregivers interpreted as the transition experience, namely interactions with the system throughout the pre-panel, panel, and post-panel phase, reviewing preliminary findings, and consulting with my thesis supervisor, it was decided that my research question could be answered without the narrative analysis, and case comparison. With the expanded research focus, my original data analysis plans exceeded what was feasible in a master's thesis.

My project maintained the mutli-layered analysis plan, however, instead of examining the caregiver transcripts and service provider transcripts as stand-alone data sets, I incorporated both sets of data and experiences temporally (i.e. organized based on timing of experiences). My findings are thus organized into three phases: a pre-panel, panel, and post-placement phase, with caregiver experiences juxtaposed with service provider perspectives and public presentations of the system in each phase. I continued with my original plan of thematic analysis of all caregiver transcripts, as well as a thematic and discourse analysis on service provider transcripts and publicly available health system documents (available on WRHA, Manitoba Health, and the Long Term & Continuing Care Association of Manitoba websites). As there were (at times) multiple iterations or interviews with caregivers due to the nature of the original project, this thesis drew on data from 55 transcripts from 22 different caregivers who were in various stages of the transition process. As well as 9 service provider transcripts, who either worked within (WRHA employee) or outside of (private case manager and non-profit organization) the health care system. As well as publicly available data on the transition process from websites for the Winnipeg Regional Health Authority, Manitoba Health, Seniors and Active Living, and Long Term & Continuing Care Association of Manitoba.

Participant Description

Family caregiver participants

To determine how many of the original 32 caregivers would be included in my sub-sample, I first conducted a key-word search through all transcripts for words such as: “paneling”, “nursing home”, “personal care home”, “home care”. This was followed by reading the transcripts to determine, to what extent caregivers had engaged with the transition process on behalf of their family member. I identified a subsample of 22 (of the 32) caregivers that described the process of transitioning (or attempting to avoid the transition) of an older adult into a PCH, from the original study[10]. In this way I utilized purposive sampling, in that I identified individuals who are particularly knowledgeable about a specific area (Cresswell & Plano-Clark, 2007). This subsample of 22 caregivers were interviewed in and around Winnipeg, MB between October 2014 and May 2015. The study included up to three iterations of interviews, with follow-up

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[10] Ethics approval is not required to analyze these transcripts as I am covered under the ethics submission for the initial project. This has been confirmed with the Human Research Ethics Coordinator.

interviews occurring approximately six-nine months after the previous interview. Time three interviews were only conducted if significant changes had occurred in care recipient and caregiver circumstances. As such, these 22 participants reflect 55 transcripts. Two (of 22) participants were interviewed once, seven (of 22) participants were interviewed twice, and 13 participants were interviewed three times. While the major focus of this research is on the transition into PCHs, seven participants included in the present analysis had not yet begun this process. Instead, in their interviews they spoke of steps they were taking to avoid or resist PCH placement for their older family member or were waiting for their family member to be placed, while residing in community or hospital. An additional ten caregivers provided retrospective accounts of the panel experience as their family member was already in a PCH at the time of the interviews. Lastly, five caregivers were providing care for someone actively going through the panel process during the data collection period.

Two participants were caring for their spouse or partner, 17 were adult children (son/daughter) caring for an older parent, one was a niece caring for an older aunt, one was a granddaughter caring for a grandmother, and one was providing care for a friend. Often, however, participants described having provided care for multiple family members (or currently doing so), either simultaneously or staggered (caring for one, and then the other)[11]. Hours of care provided by caregivers were reported as ranging from 5 to 168 hours per week, with an average of 41.73 hours. Participants reported providing care for peoples whose ages ranged from 61 to 99, with an average age of 84 years.

All but one care recipient was identified as having a comorbid condition by care providers. Most caregivers reported that that they were providing care for an individual with 2-3

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[11] These were the individuals participants indicated they were primarily providing care for, or who they were providing care for at the time of data collection

comorbid conditions, as an example one care recipient simultaneously had Alzheimer’s/Dementia, mobility issues, and arthritis. More specifically, eight caregivers were providing care for individuals with Alzheimer’s or Dementia, five were providing care for individuals with mobility issues, four were helping care recipients who had suffered from a stroke, three were providing care for someone with Huntington’s disease, cancer, arthritis, and aphasia, respectively. Additionally, care providers were providing care for other conditions such as COPD, cellulitis, colectomy, frailty, Parkinson’s, and mental health conditions. In some instances, care givers simply referred to the condition they were providing care for as ‘aging’.

Other participant characteristics are summarized in Table 1. Participants ages ranged from 32 to 74, with an average age of 55. There were 20 female caregivers, and two male. Almost half of the caregivers (40%) had or were currently co-residing with the older adult care recipient (n=9). Almost half were married (n=10); four were single, two were widowed, one was common-law with a partner, and five were separated or divorced. This sample was highly educated, with 68% (15 of 22) having completed a university or post-graduate degree, with only 1 person indicating high school as their highest level of education. Additionally, this sample had a high net household income, with 59% (13 of 22) indicating a net income of $60,000 a year or more. Caregivers reported having provided care (for one or more current care recipients) between 1 and 30 years. Caregiver participants in this study overall tended to have comfortable incomes and higher levels of education, as such there was under-representation of disadvantaged groups of carers

Table 1: Family Caregiver Characteristics

Characteristics	**N**
Gender	
Female	20
Male	2
Relationship to older adult	
Spouse/Partner	2
Son/Daughter	17
Niece	1
Granddaughter	1
Friend	1
Mean Age	55 (32-74)
Co-Resident with older adult	
Yes	9
No	13
Marital Status	
Single	4
Married	10
Widowed	2
Common law	1
Separated/Divorced	5
Education	
High school	1
Some college	1
Diploma from college or trade	3
Some university	2
University degree	10
Post-graduate	5
Net household income (per year)	
below $19,999	1
$20,000-$39,999	2
$40,000-$59,999	6
$60,000-$79,999	7
$80,000-$99,999	0
$100,000 or more	6

The timing and nature of the older adults' care transitions differed between participants, reflecting that caregiving is not a static activity, and that care needs of older adults are often influenced by circumstance, such as availability of care givers, availability of home care workers and/or services and specific medical, social, psychological, or emotional needs. Needs which may not be adequately met due to structural constraints of publicly available services and systems. In some cases, participants described spending significant amounts of time and effort keeping care recipients in the community through using public home care and other private and community services. In other cases, participants expended time navigating the health care system, including helping the older adult through hospital and interim PCH placements awaiting their eventual PCH placement. The amount of time and effort required for caregiving was in constant flux, as were caregivers' roles and responsibilities. Throughout the findings chapter, pseudonyms will be used when attributing quotes to caregivers[12].

Service provider participants

As my thesis investigated the experience of transitioning an older adult across the continuum of care and into a PCH, my criteria for the service provider participants involved those whose employment placed them in a position to assist with and/or facilitate this process. Arguably, if I had conceptualized the continuum of care in its ideal image – a comprehensive array of health and social services spanning many levels of care – this would include all service provider participants in the original study. However, my study focuses specifically on the continuum of housing care in Manitoba, this limits potential participants to those who help facilitate or inform interactions with, or transitions into, publicly funded assistance (i.e. Home Care) or housing (i.e. Supportive Housing, or PCH). Service provider participants were thus included based on employment type and/or place. All potential participant transcripts were read to determine if their interview data if they fit this criterion. Through this, I identified nine (of 22)

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[12] Ethics approval for this project does not support the presentation of linked demographic characteristics, as such demographic information is only presented in aggregate form

service provider participants to include in my sub-sample. My sampling strategy again was purposive, through identifying individuals who were particularly knowledgeable about a specific area, in this instance it involved those who were knowledgeable about the transition process and assisted caregivers in some way through the process (Cresswell & Plano-Clark, 2007).

Service providers included five Home Care Case Coordinators across 4 transcripts (one interview had two participants), 3 of which coordinated ‘traditional’ home care, while the other 2 were involved in the Self and Family Managed Care Program. Additionally, there were two Long Term Access Centre Navigators (one based out of a hospital, the other based out of the community), as well as an emergency department social worker, a private case manager, and two representatives from a non-profit organization (interviewed together). Service provider is thus a broad term to include positions both inside and out of the formal health care system that assist and/or inform family caregivers during the transition process[13].

ANALYTIC STRATEGY

My analysis had three intended goals: i) to better understand the experiences of family caregivers as they transition an older adult into a PCH (with particular attention paid to choice and control throughout the process), ii) to better understand service provider interpretations of their role as well as caregiver experiences throughout this transition (and where possible compare/contrast this against the lived experiences caregivers provided), and iii) to understand what kind of publicly available information is available to inform caregivers about this transition and whether this information aligns with the experiences of caregivers.

To facilitate this, I first conducted thematic analysis on the family caregiver sub-sample. Transcripts (55) of each participant were combined resulting in 22 transcripts. Thematic analysis

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[13] Demographic information was not collected during the interview process for this group of participants.

is appropriate when analyzing large qualitative data sets (Nowell, Norris, White, Moules, 2017). My first analytic activity was to re-immerse myself in the data, reviewing the transcripts from all participants. During this process I created case summaries for each participant to refer back to, and to assist later when determining themes. I then returned to each participants' account of the transition process to identify significant statements, such as phrases, sentences, or paragraphs that directly relate to the experience of transitions. I also noted specific points of the transition process that were particularly salient for caregivers during this phase. Ayres and colleagues (2003) contend that "no idea or insight about the data can be used to interpret the data set until it has first been shown to be important in individual experience" (pg. 872). With this in mind, when a concept or particularly poignant situation repeated across the same transcript, or numerous transcripts multiple times, I established it as a theme..

I utilized Ayres and colleagues (2003) steps to conducting within- and across-case analysis (found in Table 2), to guide my analysis. The purpose of across-case analysis is "to compare the experience of all participants and identify categories of significant statements that were common among them" (Ayres et al., 2003, pg. 874). I used these steps as a guideline, moving forward and backward across them as the analysis process unfolded. Once I identified themes, I connected each significant statement to its original context and repeated this step across the different transcripts to further check the theme. Moving between the across- and within- case comparisons facilitated intuiting, or "the critical reflection on and identification of themes as they are found in the accounts of multiple respondents" (Ayres et al., 2003, pg. 875). As such, themes were created inductively through "overreading" (Ayres et al., 2003, pg. 876), involving the close reading of transcripts for repetitions, incongruencies, and omissions, with the intent of identify meaning that is implicit as well as explicit. Overreading was especially pertinent for exploring the notion of choice and how caregivers experienced choice and control (or a lack of) in the transition process. These themes were discussed with my thesis supervisor, and closely related or overlapping themes were combined, resulting in three phases of the transition process, with 3 sub-themes respectively

Table 2: Within- and Across-Case Analysis

STRATEGY	**ANALYTIC FOCUS**	**PRODUCT**
ANALYTIC IMMERSION IN ALL INTERVIEWS	Within all cases	Sense of the lived experience of the phenomenon
IMMERSION IN EACH INTERVIEW	Within each case	Identification of significant statements
COMPARISONS OF SIGNIFICANT STATEMENTS	Across cases	Identify categories of statements common to all participants
RECONNECTION OF SIGNIFICANT STATEMENTS TO INTERVIEWS	Within and across all cases	Ascertain fidelity to original accounts
INTUITING, CRITICAL REFLECTION	Within and across all cases	Identification of themes
FREE WRITING	Within and across all cases	Answer question
ORGANIZE CATEGORIES OF SIGNIFICANT STATEMENTS BY THEMES	Set of significant statements	Essential Structure

It is important to note that interview responses are purposeful (Ayres et al, 2003, Kohler Riessman, 2002) “each story is a unique and personal interpretation of events” (Ayres et al., 2003, pg. 876). While family caregivers were going through a somewhat similar experience (i.e. transitioning into a PCH), they are not necessarily likely to interpret their experiences with the transition as similar. The narratives that caregivers provided on transitions not only give meaningful form to an experience that has been "lived through but also provide us a forward glance, helping us to anticipate situations even before we encounter them, allowing us to envision alternative futures" (Flyvberg, 2006, pg. 237). While I did not perform a full narrative analysis on caregiver data, transcripts and narratives were kept intentionally long as to not overly fragment them (Kohler Riessman, 2002). Analysis thus comprised not only the linguistic structures (words, sentences, and topical cohesiveness), but are also cognitive structures (comprised of plots, themes, and coherence (Bamberg, 2012) used by family caregivers. According to Kohler Riessman (2002), the decision to choose what aspect of the interview to analyze is shaped by theoretical interests and research questions. Through my utilization of critical gerontology, as well as a political economy of health care perspectives, with keeping my research question in mind, I was able to interrogate how the experiences of family caregivers is affected by the formal health care system, and more broadly how institutional and social structures influence their caregiving experience.

To further investigate the PCH transition experience, I analyzed nine (of 22) service provider transcripts, as well as publicly available information to examine how the process is understood and portrayed formally. This multi-layered analytic approach allowed me to further engage with my research question, providing a nuanced understanding of how family caregivers experienced the PCH transition process.

To supplement my understanding of the experience of family caregivers, I performed thematic and discourse analysis of selected service provider interviews and publicly available information regarding the paneling process in the WRHA. Health policies are not publicly available in the province of Manitoba, as such those navigating the health care system are reliant on those within the health care system to guide them along the transition. The system is thus not transparent to those using it; individual sense of coherence[14] is therefore based on expectations and assumptions rooted in the system being predictable and knowable. However, the way in which service providers interpret and implement policies can fluctuate. Policy expressions were collected through the way in which the system (through publicly available information), and service providers within the system explained the process and functioning of the transition process. Analysis of these data involved a blend of both thematic (detailed above) and discourse analysis techniques. Discourses provide guidelines for how people think and speak about any given subject in the context of a specific time and place (Mautner 2008).

Professional service providers in health and social care fields, might, for instance, invoke organizational discourses prevalent in these fields; these discourses must be understood in relation to the broader political and economic context of health and social care for older adults in Canada. Discourse analysis makes "explicit the linguistic means through which representations of reality and social relationships are enacted" (Mautner 2008:48). It studies the way in which "social dominance and inequality are enacted, reproduced and resisted by text and talk in the social and political context" (Van Dijk 2003: 352). Public materials provided by organizations, as texts, may also manifest dominant discourses, in attempts to position readers into thinking in certain ways about paneling and care for older adults (Mauthner 2008). Discourse analysis is utilized to overlay "spoken or written texts onto systematic analyses of social contexts" (Fairclough, 1992, pg. 193). To do this I read the service provider transcripts as well as public information from health care system for both linguistic analysis and intertextual analysis. Linguistic analysis examines semantics, grammar, and the way questions were answered

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[14] Way of looking at the world (Fries, 2019, pg. 9)

question and/or required probes (Fairclough, 1992). Intertextual analysis draws on “orders of discourse” (Fairclough, 1992, pg. 194), to examine conventionalized practices including neoliberalizing trends and discourses. This involves examining both what was said (and not said), and how information was presented. As such, both thematic and discourse analysis techniques were undertaken to interrogate the ways in which the transition experience is portrayed and interpreted, especially in regard to the systems gatekeeping mechanisms.

TRUSTWORTHINESS

It is important that I acknowledge that this research involves a particular theoretical framework. As such, the basis for the credibility of this research focuses on the notion of trustworthiness; as this is currently understood, this involves aspects of credibility, applicability, dependability, and transparency (Earthy & Cronin, 2008; Lincoln and Guba, 1985; Nowell et al., 2017; Tracy, 2010). Every effort has been taken to attend to methodological considerations of trustworthiness throughout the analysis, including documenting all important analytic decisions and the process of code development, and ongoing collaborative discussions with my thesis supervisor.

An aging population, a purported need for more personal care home beds, and an emphasis on aging in place, in the context of the prevailing political and economic climate in Manitoba, means that the future may involve increasing challenges related to family experiences of the transition process. Illuminating areas of particular difficulty caregivers experience with the transition experience can help to address system settings that lead to caregiver expressions of disillusion, disappointment, frustration, or burden. The intent of this research was not to dictate the path best travelled when transitioning an older adult along the care continuum and into a personal care home, but to acknowledge that although every transition is different with its own unique challenges, some experiences might potentially be improved, for instance through the nature of information and system-based help they receive along the way.

This chapter outlined my projects research design and methodology. First, I described the original project with which this thesis stemmed from. Then I outlined the multi-layered approach I took through incorporating family caregiver perspectives with service provider and public portrayals of the transition process. Following this I described both the participant and service provider participants, and my means of selection for these sub-samples. Following this chapter are my findings chapters (five through seven) that are situated temporally around the transition process. Chapter 5 will detail the pre-panel phase of the transition process, where care provision for care recipients occurs in the community, including their own residence, co-residence, or supportive housing facilities.

Chapter 5: Pre-Panel Phase

In this chapter I will provide an in-depth examination into selected family caregiver transcripts[15] of the pre-placement phase of the transition process into a personal care home. In this I explore the experiences of family caregivers as they are in the beginning phases of transitioning an older adult across the continuum of care, including experiences of circumstances that led to the personal care home (PCH) transition. This phase has caregivers providing care for care recipients in the community, including their own residence, co-residence, or supportive housing facilities. A particular focus is on how caregivers navigate systems throughout this transition as well as their level of choice and control throughout this process. Family caregiver experiences will be discussed in relation to the analysis of selected service provider transcripts[16], as well as publicly available information regarding the transition process. Service providers were located both within (WRHA funded staff) and outside of (private case manager and non-profit organization) of the health care system. The juxtaposition between caregiver and service provider perspectives serves to highlight the intersection of policy, practice, and lived experience, through illustrating the way in which caregiver agency is influenced and affected by the structure of the health care system.

Transitions into PCHs, in caregiver accounts, appeared to be predicated by the care needs of the older adult changing in such a way that they can no longer be handled at home, or have progressed to a point in which caregiver burden or burnout has occurred, and care providers are no longer able to maintain prior levels of care. This sentiment was echoed by service providers, who primarily linked the need to transition someone into a PCH to an older adults state of

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[15] A detailed description of family caregivers can be found in Chapter 4: Research Design & Methodology
[16] A detailed description of service providers can be found in Chapter 4: Research Design & Methodology

physical or mental decline. My analysis, however, indicates how structural features of the home care system, such as rigid and inflexible care plans and the task-based nature of care provision, contribute to what might otherwise appear to be changes in individual circumstances (since both unmet need and caregiver burden are relative to available supports). While at times structural breakdowns in the Home Care Program were acknowledged by service providers, these participants tended to focus more on family caregivers' inability to navigate the available supports and systems, and less on the structural features of the system itself.

Throughout the pre-placement phase, participants described frequent interactions with representatives of the Home Care Program, as well as other adjacent programs such as handi-transit, day hospitals, and so on. In this phase, caregivers spoke of managing care for their loved one in the community and positioned their own role as either actively trying to facilitate admission into a PCH, or actively trying to avoid or delay this transition. In describing this phase, caregivers emphasized their difficult experiences with formal systems, and struggles with system navigation. While service providers[17] acknowledged that caregivers can struggle with the system, they believed caregivers needed to be given more information, to become more empowered to make informed care decisions. Sub-themes presented below focus on the most common themes from the perspective of caregivers in this regard: replacing and/or supplementing care, assumptions about family care (not being heard by the system), and burden in avoiding or delaying institutionalization. Following examples of caregiver experiences, I address the system perspective based on the analysis of service provider transcripts.

REPLACING AND/OR SUPPLEMENTING CARE

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[17] Service provider is used in broad sense to include individuals with positions both inside (WRHA) and outside (private case manager and non-profit) of the formal health care system that assist family caregivers during the transition process

In Canada, home care is a program involving supportive services to help older adults stay in the community and age in place for as long as they can safely remain to do so. However, the inadequacies of the existing public Home Care Program in the regional health authorities in which this research was conducted figured prominently in family caregivers' narratives about the pre-transition phase. Common concerns included: program inflexibility (e.g., scheduling, policies about types of care provided, care plan rigidity), unreliable service (cancelled or rescheduled service), and worker inconsistency; participants also spoke of their lack of confidence in both the ability and reliability of home care workers. Public discourse on aging suggests that to age successfully one should age in place; this is coupled with a policy emphasis from the health care system to keep people in the community for as long as it is safe. The emphasis on homecare and 'aging in place' is often presented "as what people want – as their choice," however, this can shift costs from the health care system, and onto families (Armstrong and Daly, 2017). As evident in the examples below, these costs are not only financial, but can include mental (ex: depression), physical (ex: exhaustion), and emotional (ex: guilt, anger) costs on families. Caregivers' experiences of interactions with home care professionals and contacts during the pre-placement phase are critical to their ability to help care recipients remain in community. In particular, system offloading of aspects of care onto families due to perceived home care inadequacies featured prominently in many participants' accounts of deciding to start the PCH placement process.

Tara's example highlights how, at times, policies around what services publicly available home care can be provided are inadequate. Tara cares for her mother who resides in a supportive housing facility. These facilities are unregulated residences with varying packages of service supports available to residents in a home-like setting, developed as alternatives to PCH placement. Supportive housing facilities come at a greater personal cost to residents, who are required to purchase service packages (over and above the basic package included in the cost) based on the level of care they want/require (although public home care may also be available to residents). The costs for supportive housing vary depending on the facility, but some income-based subsidies are available[18]. Previously Tara's mom had been living independently, but since her move into supportive housing there has been confusion over care responsibility:

> Now that she's in supportive housing she has access to less personal care … I brought it up once before with her case coordinator and was told "no the showering is all a part of the services that they're offering in supportive housing. So, homecare will not offer her any other personal care". … she requires the care, but because she's in something called supportive housing, she's not entitled to it.

Tara's mother is incontinent and requires showers not only for general hygiene but for health reasons including skin integrity. However, when she expressed these concerns to her mother's Home Care Case Coordinator, the coordinator informed her that the one shower a week provided by the supportive housing facility in the basic care package was deemed adequate (by the system), and her mother will not be receiving additional showers from Home Care. And yet, Tara's mom now received fewer showers than she was when she was living independently and receiving public home care services in her apartment. Since the service packages in supportive housing require private purchase by residents (in contrast to home care, which in this region is a no cost service), Tara's mom is now effectively paying for less care than she was previously receiving at no personal cost. Although Tara expressed concern to the Home Care Case Coordinator of her mother's medical needs for more showers, her mother did not receive them. Tara and her mom now have three options: a) pay more money for a private care worker/service package that offers more showers; b) Tara could help her mother shower; c) her mother goes

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[18] http://www.wrha.mb.ca/ltc/housing.php

without the additional showers. All three of these options have their own financial, mental, emotional, and physical costs associated with them. From Tara's perspective, since public home care is available to residents of supportive housing, her mom should be entitled to the same level of service she was receiving in the community, not less. Tara's example illustrates how inflexible Home Care Program policies affect care receivers; Tara herself expressed feeling disheartened and distrustful of the Home Care Program. Distrust of the system can potentially result in distrust of people within the system (Shaufeli, Leiter & Maslach, 2008; Funk et al., 2017; Guberman et al., 2006). This ripple effect could not only affect further interactions with Tara's mothers Home Care Case Coordinator, but future interactions that she herself could have with home care. Throughout their daily lives, individuals "act unconsciously according to their habitus" (Collyer, 2015, pg. 689). In this way people make choices, develop ways of coping, and interact with differing systems through the way in which they embody habits and skills they have learned throughout their life experiences (Collyer, 2015; Fries, 2019). However, Tara's example shows the ways in which disappointment and unpredictability in the health care system (through the way it responds to health care needs), can affect the wellbeing of caregivers (through her feelings of distrust and disappointment) (Fries, 2019).

Home care services can often be constrained to specific tasks and times which can limit the independence of care recipients (Armstrong and Daly, 2017). Additionally, the services that are allowed to be offered by the Home Care Program can be restricted based on policy. Service providers, in particular the Home Care Case Coordinators acknowledged that Home Care is often a regimented and inflexible program, and services do not always meet the needs of individuals. One coordinator stated: "our policy is not to repeat what's out in the community." In this instance, she was specifically speaking of when care recipients might require assistance with meal preparation, and how they refer those individuals to the Meals on Wheels program, despite it being a pay for service. She further elaborated that "sometimes that's a little awkward because you're also sort of looking at eligibility for homecare as well doing a referral and sometimes the referral makes a lack of eligibility for homecare resources." This operational policy stance is reflected in care decisions like Tara encountered, in the way in which the Home Care program would not provide assistance with showers for Tara's mom as this was a service already available through the supportive housing facility. Despite this, many service providers expressed that their goal was to provide client-centred care to meet the unique needs of the older adult. This contradiction highlights the tension that exists between the needs of family caregivers and fiscal requirements to limit resources available to what is strictly deemed necessary.

Transitions such as those described by Kelly below also showcase the struggles caregivers can have when attempting to access home care services, especially for those who live rurally outside of Winnipeg. Kelly provides care for her husband who is affected with stroke related cognition problems as well as Parkinson's. Finding appropriate and adequate home care was a struggle:

> I panicked … I phoned everybody that we had known in [*rural town 1]* looking, after [*rural town 2]*, to start saying "who do you know that has ever done homecare" because they just didn't have the manpower out there to … provide it. … We ended up getting homecare. … a very good friend of mine had a niece who lived out there who had never done homecare, but she was a lovely person and she came so many nights a week when the others couldn't to get him into bed. … [home care] assessed her, and she was a good common sense, head on her shoulders, pleasant person.

Kelly was told that the Home Care Program did not have the staff available to provide care in their home town. She had to reach out to her own social network to find someone who had the knowledge and ability to provide the services they required; this person was not already a public home care employee, but according to Kelly was hired by the Home Care Program. Kelly also said that home care offered to set up Self and Family Managed Care (SFMC)[19], but at a time she was dealing with her husband's return home from the hospital (adapting her home to accommodate her husband, selling two vehicles to buy a van so she could transport him), she felt the administrative work required with that option would be too much for her to handle. Although Kelly was able to care for her husband at home throughout the first and second interview of the study, his increasing care needs and lack of fit between her husband's condition and their inappropriate housing layout prompted a move into Winnipeg (considerable home renovations were needed to keep him in their rural home). Kelly's experience with the Home Care Program due to poor availability in rural areas is indicative of the level of work required at times of caregivers simply to ensure that older adults receive adequate care.

Home care is funded by the provincial government but provided by the regional health authorities (RHA). Kelly's experience was within a RHA not represented by the service providers interviewed as part of this study (who were all WRHA employees). Nonetheless, research has shown that the main challenge with rural home care delivery is a "lack of health human resources, lack of support systems and local resources, limited transportation, and the requirements to travel long distances and hours to see very few clients." (CHCA, 2008, pg. 2). The consequences of not meeting older adults care needs in community can be quite severe, resulting in an older adults "inability to live in a safe environment" (CHCA, 2006, pg 13). In rural communities, there is a reliance on family and/or communities to support the delivery of home care, as the low-number of health human resources (home care workers) dictates the amount of home care that can be offered (CHCA, 2008). As insufficiencies in Home Care

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[19] The Home Care Program has an option for direct managed care (Self and Family Managed Care) that allows either the individual receiving care, or their family member, to accept responsibility for hiring, coordinating and managing their own private personal care providers.

availability often result in family caregivers replacing and/or supplementing care, the risk of caregiver burnout is increased. In Kelly's case, there was no one readily available in the existing Home Care Program that was able to provide care, and the system had to make allowances to ensure her husband received the care that he required. When care needs cannot be met by the system in rural settings, it often initiates a move to an urban setting, this can result in emotional and financial challenges for older adults, as well as an added cost to the health care system, if the older adult requires care in an acute care or personal care home (CHCA, 2006).

Kelly's apprehensions around SFMC were well founded, as this system can be quite overwhelming and onerous for caregivers. The Self and Family Managed Care Case Coordinators we spoke to stated that the program often requires a family member to act as a manager of care, known as a "family manager" to do the "training, hiring, orientation, make sure the person [employee] is competent" for the potential care workers. As such, this program tends to privilege those with higher health capital (Shim, 2010). Cultural health capital purports that "cultural skills, verbal and nonverbal competencies, and interactional styles" are critical to the ability to engage with the health care system (Shim, 2010). Caregivers' ability to navigate the health care system is thus influenced by their level of education, socioeconomic status, and interpersonal skills. SFMC, a system that allows family caregivers to hire their own care workers, responsibilizes the administration of care work onto family caregivers. While the regularity of care workers (consistent staff) and time of care visits is appealing for many care recipients who are tired of the existing Home Care Program, it comes at the cost of available time, as well as emotional and mental energy of family managers who now have to take on hiring, firing, training, audits, taxes, and other administrative tasks. While the service providers interviewed said SFMC puts "control into the hands of the caregiver", it also takes away control they have over their own lives, as this program can be quite time consuming and require mental and emotional energy to maintain.

As noted above, participants often characterized the care plans delineated by Home Care Case Coordinators as rigid and restricting. These care plans, and the task-based nature of home care visits, provide little time for social interaction between workers and clients, or for anything ‘extra’ or ‘over and above.’ This was noted by Lorraine, who previously provided care for her husband (she was bereaved at her T2 interview). Her husband was diagnosed with cancer, and while her experiences with Cancer Care were “absolutely amazing”, she did not have the same experience with Home Care:

> They said they couldn’t put someone in to watch my husband or to prevent a fall, but they said if I left the dishes, they could do that. Well that’s pointless. I have a dishwasher. To me they should come in to do a job that you can’t do or that would assist you in being able to get out to do your job.

Lorraine wanted a worker present to help to help her husband move around the house and prevent falls; at least, she would have liked a worker to check in on him a couple of times a day. The Home Care Case Coordinator informed her that that helping with transfers and mobility placed an undue safety risk on home care workers due to his fall risk, and as such, preventing falls was not within the scope of the care plan. The risk to Lorraine’s own safety was not seen as a factor that should necessitate the PCH transition process, but one that was acceptable due to her co-resident status. Moreover, if Lorraine wanted someone to check on or stay with her husband, she would have to hire a private companion[20], or stay home to do so personally. Home care is not a responsive program, but a regimented one; tasks are not tailored to day to day needs of clients and family caregivers but are predetermined by an assessment made by a Home Care Case

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[20] A private companion is a privately hired care worker who can provide a broad range of services ranging from social emotional to medical care depending on the needs of the family or care recipient.

Coordinator who may only interact with the client at the time of that yearly assessment. As such, the Home Care programs regimented, task based processes assumes that older adults care needs are static, with medical needs to be treated, leaving no opportunity for participation or rehabilitation (Estes, 1999). Lorraine's example highlights how care needs fluctuate day to day and can extend beyond the scope of the care plan. It also demonstrates how caregivers can be put into situations where they have to sacrifice their time or plans to ensure client safety. This can lead to increased caregiver burden and burnout, resulting in the need to transition clients to more intensive care environments, i.e. supportive housing or PCHs.

Service providers noted that respite service was a common request from family caregivers, whether they were living with the care recipient or not. One service provider commented "they just want to know that somebody is with their parent". Service providers expressed that this was caregiver's way of "asking for some backup in terms of their time and availability". Often, however, this was prefaced with the need for caregivers to understand and acknowledge when they are suffering burden or burnout, and when to look for help to get respite. The system offers respite supports to alleviate caregiver stress and burden only when caregivers declare a state of burnout, in this way the system does not support the health of caregivers, but treats the illness of them (Lilly et al., 2011, pg. 103). This completely pathogenic and reductionist health care system results in a reactive process that does not ensure the health of caregivers, but waits for a time of crisis to respond. This pathogenic paradigm is reinforced through service provider reactions to care giver burnout, with one service provider stating: "I find a lot of caregivers need to kind of burn out before they will say I can't do this anymore or my mom can't do this anymore". This, however, requires caregivers to have the ability to recognize when caregiver burden is becoming too onerous. Caregivers are often unaware of respite services, or the parameters of the respite service are often “aligned with health system goals and needs, rather than caregivers articulated needs” (Lilly et al., pg. 108). Available respite is often for time-limited tasks, and as such, in some regions some caregivers are not even able to leave the house, though they might be able to gain short bits of time to themselves (Lilly et al., 2012).

Although caregiver burden or burnout was a concern expressed among many service providers, some conceptualized the problem as one in which the needs of older adults came to outweigh the caregiver’s ability to provide care. Other service providers however, identified caregiver burden as connected to more and more work being offloaded onto caregivers, stemming from deficiencies in the organization of the health care system – in other words, a recognition of “structural burden” (Funk et al., 2017, pg. 9). One such service provider claimed:

> Things are very reactive in the system and things tend to be pushed and pushed and pushed until you are at the breaking point for families, [it] ends up being urgent respite or someone passes away or caregivers burnout and a lot of that is resource based because they’re going out of the hospital earlier and maybe not with a complete care plan, we don’t have the time to do things the way that they are designed to be done

Cost-saving motivations to send patients home “quicker and sicker” (Armstrong, 2011; pg. 32), where adequate supports in place at home are lacking, can result in an over-reliance on family caregivers. Burden is thus not merely a caregiver’s inability to cope with care demands, but further exacerbated by system pressures to discharge patients back to community with insufficient supports in place to maintain them there (Purkis & Ceci, 2015).

In addition, participants often spoke of the frequency with which they had to supplement or replace cancelled or delayed home care visits. In most Canadian regions, public home care services are clearly described to families as not a “guaranteed service”; families are told they must have a back-up plan in place if a home care worker is unable to make a scheduled appointment (Auditor General of Manitoba, 2015). In the extreme, some participants in this study described leaving paid employment early, or calling in sick, even postponing or not taking vacations as they serve as the safety net in the event that home care falls through, and they noted not knowing who would be available to provide that care. The need for caregivers to rearrange their schedules was noted by many participants who described interactions with the Home Care Program. Courtney, who provided care for her mother (and father), went to great lengths to manage this problem:

> We found that homecare for the first and second year were probably one in three no show*(s)* or sick calls. So, I would [get] calls at 11:30 at night saying "we don't have anybody. Will your mom be all right?" No, she won't be all right. "Can you see if you can get anybody?" Most of the time they didn't have anybody. So, I would get up and go and sleep over at mom and dad's and get up and go to work and leave from there. I remember sometimes waking up and not knowing where I was, which house I was in, what day it was, if I had clothes there to go to work or anything else…. Holidays would come up and they would tell you they don't have enough staff and ask us "can you guys manage over the holidays?" And we wanted to manage the best we could and have her with us most of the time. So, we would say okay. So, we would manage holidays, long weekends, whatever came up and we would fill the gaps for homecare because they didn't have enough staff.

Home care is increasingly utilizing a rigid, task-focused model of service provision, in which workers are given a limited time to accomplish tasks and then move on to the next client (Armstrong & Armstrong, 2017). In this way, care is fragmented and bureaucratized, resulting in the treatment of the individual illness or ailment, and not the whole person. Despite a rhetoric of consumer choice, older adults and families "have little or no choice about what and how much care they receive" (Armstrong & Armstrong, 2017, pg. 50). This can be attributed to a focus on fiscal responsibility over the long-term social care of individuals requiring home care, reflecting an increased focus on "meeting primarily short-term and emergency needs" of clients, largely driven by the broader needs of the acute care system (Funk, 2016, pg. 83). This shifts more responsibility for care from the Home Care Program to the older person and their families.

Should something unforeseen happen (e.g. a client is injured during the care appointment or needs emergent care), or if there is a shortage of workers that day, care workers might be late, or appointments may be cancelled.

Families supplement or replace the work that should be provided by home care, a program meant to assist people to stay in the community. Courtney not only often stayed the night at her parents to provide the overnight care they needed, but also hired private home care two nights a week, to supplement or replace home care visits. This happened regularly for other caregivers as well. Courtney described the impact of this on her both emotionally (e.g., feeling agitated or drained) and mentally (e.g., exhaustion). Indeed, collectively, the findings from this study suggest that the need to supplement or replace cancelled or delayed home care visits affects not only the personal lives and finances of caregivers, but also their professional roles, as some care is time sensitive and would require them to leave work.

Service providers often noted that families were having issues similar to Courtney's, in that they were encountering cancelled or missed appointments. One such service provider noted: "they're saying there's not enough resources in the community. Homecare calls in sick and nobody comes to replace and there's no communication to the family…" Adapting to home care staffing issues significantly affected care providers day to day planning and burden load. However, this tended to be equated by service provider participants with how this affected *their* ability to do their job rather than the effect on caregivers. While Home Care may be represented by service providers as one unified program with one point of access (i.e. the Home Care Case Coordinator) for families, there is not only a Home Care Case Coordinator (responsible for assessments and creating care plans), but also a Nursing Coordinator (organizes Home Care Nurses when clients may need medical treatments such as wound care), and a Home Care

Resource Coordinator (schedules non-professional home care workers to perform services as laid out in the care plan). The Home Care Case Coordinators we interviewed noted that often the phone calls that they are receiving (re: missed or cancelled appointments) should be directed to the Resource Coordinator. One service provider stated: “there’s a little role un-clarity in that and they also say well don’t have the clients call us because then we can’t do any work because we’re bombarded by client calls, so they’ll often stream those calls that should be going right back to the case coordinator”. The “role un-clarity” and the siloed nature of care delivery within the Home Care Program results in undue stress for caregivers, particularly in not knowing who to go to for information or answers.

The siloed systems within Home Care (i.e. nursing, care plan creation, and service scheduling) results in a fragmented and pathogenic understanding of a care recipient, instead of a salutogenic assessment of the whole person (Segall & Fries, 2011; Quehenberger & Krajic, 2016). Fragmented systems and care, in which practitioners focus on lists of tasks to be completed, rather than engaging with older adults (and caregivers) as persons can shape caregivers’ interpretations of their environment in ways that erode their sense of coherence (Quehenberger & Krajic, 2016). Sense of coherence is “an embodied disposition for effective coping” (Fries, 2019, pg. 9), a feeling that one’s life events are predictable. Those with a high sense of coherence are “highly resilient and adaptable in the face of life’s obstacles” (Fries, 2019, pg. 9). Conversely, a low sense of coherence can explain why some people can be affected negatively or become unhealthy during particularly stressful times. The health care system itself creates situations that erode sense of coherence, which can affect the health of caregivers.

Courtney’s mother’s condition progressed, eventually it was determined (during a period of hospitalization) that home care could no longer adequately support her at home, and she was transitioned into a PCH from hospital. Courtney expressed feeling some relief after her mother was paneled, as previously she had been providing personal care (baths, ADL support), administrative tasks (dealing with finances), meal prep (grocery shopping and cooking), therapy (walking, and spending time with her) as well as and cleaning, doing laundry for her parents. But when she was told that “homecare can’t support her [mother]. She’s a two person assist now. She needs some oxygen. We can’t really have her going back home,” Courtney was now faced with maintaining her father at home and providing care for her mother in the PCH. Caring for parents in multiple locations was common for participants, who would be required to navigate both a convoluted and fragmented Home Care Program as well as the entry into PCH and subsequently providing care after placement.

For some caregivers, publicly provided home care services were not even perceived to be a viable option. This is the case for Kimberly, who hires private home care for her co-resident mother with mobility issues, supplementing her own efforts in an attempt to keep her out of a PCH. However, Kimberly herself wonders whether keeping her mother at home is ‘sensible’:

> If I was making sensible choices for her, I would have put her in a long-term care facility, but I’m making care for how she wishes. … traditional [public] homecare won’t work… she gets up very early in the morning between 5:30 and 6:00 and [public] homecare doesn’t start until 8:30/9:00 right. So, morning care is not an option. And she wants to be in her bed and the way she’s got her bed, [public] homecare wouldn’t be able to transfer her because they couldn’t get the Hoyer machine into [her room] …

Public home care is not perceived as a viable option due to such restrictions. Doing everything she can to respect her mother’s wishes by preventing a move into a PCH requires Kimberly to constantly be available, and to be home at specific times; Kimberly described this as, at times, as being “absolutely draining.” Kimberly’s example is indicative of the work caregivers have to provide when neither institutionalization or public home care are available options; the work involved in this takes a toll on caregivers who now have to balance their lives but also the lives and wellbeing of their loved ones.

When service providers discussed care recipients with whom home care may not be a viable option, the problem was posed as that of the care recipient rather than that of the system. This individualization of caregiver problems results in problems such as Kimberly's being interpreted as private troubles, and not a wider systemic issue. For instance, one service provider noted "some people are not a good fit. They're a square peg for a round hole." Service providers expressed that caregivers and clients have to make accommodations to their schedules to be eligible for the program. To the extent that, as they believed, care plans were client-centred, care plans themselves are implemented within the confines of program availability and scheduling. Often service providers noted they would suggest SFMC to clients and their caregivers if they were not a good 'fit' for the traditional Home Care Program. However, as noted previously, this requires family members who are willing and capable to serve as family managers in organizing and coordinating the care.

In sum, participants' accounts indicated that caregivers often need to work out their own solutions to problems arising from system non-response, or to responses that are, from their perspective, insufficient or inappropriate. The system is underpinned by assumptions that caregivers will know what to ask for or who to talk to in order to receive assistance. Some caregivers also noted how dealing with these problems led to making conscious choices to decline public homecare services and/or hire privately, or scale back or change their paid work arrangements (see Jen's upcoming example). Their narratives also highlighted how a model of home care that is regimented, rigid, and often unreliable can generate mental, emotional, and financial burnout for family caregivers. For instance, as caregivers often had to supplement or replace the work done by home care workers, providing care at home was described as reaching points that were overwhelming which indirectly would lead to eventual PCH placement. In this way, interactions with the Home Care Program could be considered an important, albeit indirect, contributor to the transition into a PCH.

ASSUMPTIONS ABOUT FAMILY CARE (NOT BEING RECOGNIZED OR HEARD BY THE SYSTEM)

As well as specific concerns with home care, participants often expressed feeling ignored or misunderstood within the broader health care system. They described disappointing interactions with healthcare professionals, and their frustration with unanswered calls as well as mixed messages from within differing health care silos. In essence, there was a strong sentiment from caregivers that that those working in the system did not pay attention to the constraints on their own lives and assumed that families could/would provide care. Caregivers often spoke about the added stress, frustration, and desperation that accompanied feeling not recognized or heard by the system. The feeling of being brushed aside by the health care system led to negative transition experiences, and at times, added to the burden and burnout that caregivers reflected on.

This was the case with Jen, who is a co-resident caregiver for her mother. She describes her confusion over the amount of care to which her mother was entitled or eligible due to conflicting information she was receiving. In this regard Jen describes differences between the approach of an hospital occupational therapist, and the Home Care Case Coordinator who was setting up a care plan for Jen’s mother’s discharge back into the community:

> At first the occupational health nurse said “well you’re there in the morning. You could easily get her dressed and get her breakfast and things like that”. And I mean when someone says that it doesn’t seem like such a big ordeal. But when [mom] first came home she wasn’t sleeping through the night. So, I was getting up with her three times a night to help her to the bathroom, so she didn’t fall again and hurt herself. And then trying to get ready myself for work. It’s not the same as dressing her; like just assisting someone to dress when somebody has had an injury like that it’s much slower. They’re not as capable.

> [The Home Care Case Coordinator] said well we'll have someone come in the morning to help her get dressed and ready for the day and give her a wash. And then a lunchtime one to make sure she had lunch and she was even gonna extend that to weekends, but we said no, because sometimes you don't always be on that schedule of having someone coming and things like that. But she was kind of the opposite of what the occupational health nurse was. The occupational health nurse was of the view well you're there. You can just do it…

Although Jen ultimately determined that accepting more public service came with a cost she was not willing to pay (having to shape one's own life to inflexible schedules), she also believes that the occupational therapist did not recognize or consider her personal constraints as a family caregiver (working a full-time job). Similar interactions, in which health care professionals made assumptions of family care availability and ignored the possibility of other commitments, were recounted by other participants in this study (especially co-residing family caregivers). Co-residing family caregivers often expressed the challenges involved with these living arrangements; while it allows them the ability to provide care for the care recipient and help them remain in community longer, there is also the added level of expectation from both the care recipient and the health care system that they are there and can and will help with the care.

Mixed messages received by families were acknowledged by service providers, who at times noted how this could reflect differing priorities existing across the health care system. One service provider also stated: "the health care system perhaps is, not coordinating, because we're all underneath the same health authority but there's tens of thousands of employees so our departments can be fragmented from each other". A lack of role clarity, system priority, and communication across silos is reflected in comments from service providers that they themselves do not understand how other systems work; for instance, as one service provider stated: "I don't pretend to know their system and they really don't know ours either". Despite this, many care providers described situations where service providers in one area (ex: hospital occupational therapists) would convey information about services in another area to families (e.g. the type of care that Jen could expect from the home care program for her mother). Inconsistent information such as this resulted in confusion and undue stress on caregivers who would have to ascertain which service provider was giving the most accurate information.

Caregivers often had particular assumptions about the way in which the system would and should recognize their needs and react to their struggles. Fries (2019) contends the "taken-for-grantedness" (pg. 13) that individuals have for formal health care services reflects the way in which they have an expectation of the health care systems medical security (i.e. its ability to provide care when it is needed). However, the system, through the type and amount of services it offers defines the way in which it will provide services based on an artificial definition of patient's needs. This misrecognition can result in "what is deemed legitimate and healthy can be temporally, geographically, and socially relative" (Aronowitz et al., 2015, 403). This misrecognition is evident with the case of Kimberly. Kimberly's mom had mobility issues as a result of a leg amputation, as well as other co-morbidities including COPD. This resulted in Kimberly providing between 30-40 hours of care a week in addition to working full time. Kimberly stresses that one of the reasons why providing care for her mother is so stressful is because she is "providing care for her according to her wishes," which are to remain in the community and out of a PCH. She had wanted to receive a commode for her mother but was told they needed a public home care assessment to be eligible for a publicly provided one. Home care assessed her and created a care plan, but Kimberly's mom was resistant to home care support because she was scared that she would be assessed and "shipped into a long-term care facility." Following this resistance Kimberly felt they were labelled as difficult and decided to try to manage on their own on the direct managed care program (Self and Family Managed Care).

> So, they've already kind of labeled her as not wanting service. So, I say that's fine for about the first six months and then somebody tells me [about] this family managed care… I think I emailed them and they send you back an auto-reply saying thank you for this and it takes seven days before we even look at your request …Finally somebody gets back to me and they said oh the application has to come from your homecare case coordinator and according to our system you're open to the homecare case coordinator…It turns out my homecare case coordinator was on maternity leave and they hadn't filled the position. They couldn't assign it to somebody else, so I waited basically two months before they assigned [a case coordinator]. All I'm basically asking is for the application form. Just send me an application form for the thing. When somebody from self-managed care finally called to set up the initial appointment then they said before we can do that, we need an updated care plan from homecare which set us back then a couple months… So, we wait all this time and then you have to wait more. They do say in your application process that it's this long; you know don't call us; we'll call you. You can expect a wait of 6 to 12 weeks. But it just turned out that that was never a viable option …At [one] point I said I give up, but at least give me regular homecare, because it was becoming onerous and onerous. And [they said] we can't do that cause you're open to self-managed care and they might close their file…

For Kimberly, extended periods of waiting for responses and action, and the lack of readily available information about how to access Self and Family Managed Care, generated considerable expenditures of time and effort that in this case, were in vain. Kimberly expressed that the stress of balancing her mother's care as well as her full-time job and attempting to follow up with people in the system was at times too much to handle. The bureaucratic melee that Kimberly had to participate in to initiate care for her mother was overwhelming. Kimberly expressed guilt that at times she stopped following up as much as she should have because she was exhausted and tired of non-response from the system. This resulted in feelings of frustration and failure from Kimberly regarding the time it took to eventually initiate care.

Kimberly's mother fell through the cracks of the Home Care Program. As Dalmer (2018) has recently suggested, interventions and assessments required by the Home Care Program are "designed of isolation from the social, cultural, and structural constraints experienced by" (Dalmer, 2018, 20) family caregivers and clients – a phenomenon stemming from the primacy of the “biomedicalization of care” (Dalmer, 2018, pg. 19). Examples of extended periods of silence and non-response such as this appeared to be commonplace between caregivers and Home Care Case Coordinators in this study, and although participants tended to interpret this as the result of strain on the home care system, it also had the effect of making them feel that the needs of clients and families were not heard or recognized.

When care transfers occur, shifting the responsibility of overseeing individuals from one professional to another within the health care system, there is the risk of care inconsistency, or in the case of Kimberly, becoming lost in the bureaucratic process of case load transfers and assessments. The onus to receive an updated care assessment was pushed back on to Kimberly to facilitate. Kimberly begrudgingly took on this task as she felt that she had no other option. When caregivers are faced with what could be perceived as unsurmountable workloads to facilitate care for their loved ones, it can lead to feelings of agitation. However, as service provider participants mentioned, this does not end in their favor. One service provider went so far as to say:

> Interpersonal skills is a big one [that helps with system navigation], approach, if a person comes across as super abrasive and accusatory, a person may be less likely to try as hard to help that person. We try really hard to look past that and focus on what the needs are. But I can see that there would be a lot more reluctance to go the extra mile for a person when they are treating you like that

While service providers in this study acknowledged that issues with the health care system could generate strong emotions in caregivers, they tended to fault caregivers’ ability to cope with the system, and not the system itself. This type subordination, “allows the naturalisation of domination” (Navarro, 2006, pg. 19). The misrecognition, or symbolic violence, creates the subordination of caregivers to the health care system, it allows for the exercise of power over those who need to navigate through the system (Navarro, 2006). The taken for granted assumptions of who the health care system recognize as legitimate for receiving care, result in assumptions around who is worthy of receiving care, or the form of care they can receive, “this symbolic power is the very foundation of dominance” (Navarro, 2006, pg. 19). Service providers likewise spoke of the constraints on their ability to create adaptive care plans; for instance, one provider stated: “there’s not always a viable plan. Sometimes it’s just not gonna work. And it’s not so much that we’re saying that you are not eligible, but we’re putting it on them – how are you going to make this work?” Statements like this showcase the primacy of system needs over the needs of clients and families.

Unlike the participants who are attempting to avoid PCH placement for their loved ones, Lorraine (and her aunt) had reached a point where they both believed it was no longer safe for her aunt to remain in community and were actively trying to facilitate placement:

> I’ve been struggling to find services, it’s always a long waiting period to be assessed and a long waiting period after assessment to put something into place. And I don’t find they’re listening to her or me as to what her struggles are… As her abilities have declined, we can’t seem to get anyone to listen [when we say] no she can’t do that anymore; like she’s been asking for personal care placement because she was always falling. She’s a large lady so she can’t get up without paramedics coming and standing her up. The geriatric assessment team, the occupational therapist that came out, she just looked at her and said you don’t want personal care. You won’t have any choices. Well I mean the choices for her are already gone and sitting in her suite is not a choice. It’s what she has to live with …We asked homecare for her to be paneled, and she said she doesn’t qualify.

Lorraine, like Kimberly, experienced long service waits (in this case, for assessment) as excessive. This lack of timely response meant that Lorraine was becoming increasingly frustrated as she interpreted health care providers as simply not recognizing that they just cannot maintain her aunt at home safely any longer. This unfortunately became a situation in which an emergent health issue (hospitalization) precipitated her aunt’s move into a PCH. Lorraine was one of many caregivers who was actively providing care for multiple care recipients, her aunt and husband (mentioned previously). Kimberly also had previous caregiving experience for her mother, father and uncle, and has found that her experience with her aunt was the biggest struggle because they “couldn’t get anyone to listen.” Not being recognized as in need, or having your needs acknowledged by the system can be disheartening to caregivers who feel like they have nowhere else to go. One service provider admitted “[sometimes] it takes a month to a month and a half to get the service in place and in that time the caregiver is so burnt out they just can’t do it anymore”. This was simply acknowledged by many service provider participants as a reality of the system. The gap between requesting services, assessment of need, and implementation of services can be overwhelming for caregivers. Additionally, the information work being required of family caregivers can be onerous and time consuming. Information work both informs and guides the care that caregivers facilitate for care recipients, it involves the steps required to seek out, evaluate, use, or share information (Dalmer, 2018). This is work that must be performed in order to successfully navigate the system, however, this work is done in vain if caregivers needs are not being recognized. This often resulted in a feeling of loss of control over the care journey.

A biomedicalized approach, involving task-based care aimed at treating individualized pathologies and illnesses, within the Home Care Program, and systemic pressures to alleviate the high costs of hospital care, means that elements of the program are “increasingly drawn toward the provision of medically related, medically supportive, and/or medically oriented services” (Dalmer, 2018, pg. 19). The organization of the Home Care Program results not only in the fragmentation of care, but fragmentation of the person being cared for. Specific task-based assignments fit care options into pre-specified baskets, whether it be nursing care, social-emotional care, or ADL supports. However, the quick time in which home care workers are expected to perform tasks results in little time for social-emotional care. Standardization means little agency or autonomy is allocated to front line health care aides (HCA) that interact with clients and families in day to day exchanges. HCAs cannot make care decisions or provide social care as these fall outside of the scope of their allowed practice, or the specified amount of time they have to accomplish tasks. The task-based nature of care in Home Care Programs can result in institutional failure in caring for older adults, as HCAs are relied upon to update the resource coordinator, who will then need to update the case coordinator about any care plan changes that care recipients may require or changes in health status that should be addressed. However, this can result in information being lost or misinterpreted, as the timing of HCAs day may not allow for immediate phone calls to relay information.

In sum, participants tended to emphasize that they and their needs were either not being recognized within the health care system (which appeared to generate frustration and stress), or that they were hearing mixed messages about care policies and processes, leading to confusion. This was compounded by long waits between assessments and services that resulted in caregivers feeling forgotten or brushed aside. There is a taken for granted assumption that individuals have access to the health care system when it is needed (McDaniel, 1997). The health care system exercises power over caregivers and older adults based on the what they determine health care needs to be, and the services that are designed to meet those needs. The emphasis within the health care system is on keeping individuals in the community for as long as it is safe to do so, however, this is based on assessed medical need. The assumption is that care will be provided by informal caregivers with the support of the system (through home care or other assorted programs). However, this assumes that the system recognizes and acknowledges the types of care and services that caregivers need. When needs are misrecognized, and caregivers feel they are not being heard by the system they can develop a sense of hopelessness, that will result in the degradation of the trust that they have in the system to properly care for their loved one.

The health care system reflects and functions in ways oriented to system needs and challenges, and to a biomedical approach, and not the needs of clients or families, despite claims of being client-centred. Even the language of ‘client-centred’ suggests they are not considering caregiver needs or concerns. However, such a system relies heavily on the unpaid care work of families, and privileges professional expertise (Dalmer, 2018). Caregiver participants often spoke of not knowing where else to go, or who else to talk to, and feeling that they had exhausted all efforts they could think of. The information work required to navigate the system is not something inherent to providing care, but one implemented into an overly bureaucratic and fragmented system that places the onus on successfully navigating onto empowered and informed caregivers. This significantly impacted the experience of caregiving for many and led some to feel that they were no longer able to provide care.

BURDEN IN AVOIDING OR DELAYING INSTITUTIONALIZATION

For the 40% of participants that initiated co-residence -either moved their family member into their own homes or moved in with their family members to help provide care – this was often characterized as being the result of having no other option, because there was no one else to provide care. In the rare case, caregivers noted that it was something that they willingly took on as a means of filial responsibility and expectation. For some participants, this was part of an active strategy to avoid the institutionalization of their loved one (normally characterized as so undesirable so as to be not a viable option). It also appeared to be easier for those with a higher socioeconomic status, or the financial means to do so. Indeed, for those who were able to delay transitions along the continuum, particularly into PCH, they appeared to do so by incurring greater financial private costs (e.g., installing adaptive devices, hiring private companions, private physiotherapists or occupational therapists).

Some caregivers, such as Mary, characterized the added emotional and financial costs of delaying institutionalization as something she took on willingly, and yet at the same time inevitable, due to her strong commitment to family care (e.g., expressed in sentiments such as "how could you not?" and "we owe her, so it's fair"). Mary's commitment to family care is evidence of her perceived obligation to her commitment to maintain a valued sense of identity of her interpretation of a good daughter. Mary moved her family back to Manitoba from another province when she realized her mother was needing more extensive care that could not be managed from where she lived. Although she wanted her mother in a PCH, her mother was not assessed as needing that level of care, and was only offered supportive housing as a viable option:

> She's physically able to do the tasks so she qualifies for supportive housing. They're going to go in and say get up… She's not cognitively able to do these things. However, she's not going to qualify for a PCH as long as she's physically able to do the things. She needs more assistance than is available in supportive housing, but that's apparently my only option for now. So, what I've decided to do is skip over supportive housing completely. But I'm gonna wait it out. I'm gonna say to myself that what support they provide in supportive housing is no more than I'm providing right now.

Mary felt that her mother was eligible for, and should have been paneled for a PCH, but voiced being told by her Home Care Case Coordinator that since her mother was physically able to perform ADL tasks (despite her cognition level), she would only be eligible for supportive housing. Mary instead chose to keep her mother where she was (in a close by assisted living facility). After moving back to Manitoba, Mary had worked a full-time job until she determined that her mother's care needs would not allow for this. Financially she was able to quit her job and remain working freelance to provide care for her mother throughout the day. To maintain her mother in the assisted living facility rather than make the move to supportive housing, Mary took a significant cut in income, working two days a week instead of five to provide care for her mother in her mother's home, where she frequently spent the night. Mary spoke of the personal costs caring for her mother resulted in, stating "we haven't been out in forever. We used to have friends…" Mary represents an extreme example of a caregiver that sought every possible way to defer institutionalization until a suitable location was secured; in this regard her ability to do so was connected to her position of financial privilege.

Mary expressed feeling "penalized" by the Home Care System by providing care herself and not utilizing their services, declaring "I don't think that we should be penalized for not having used enough homecare or for the fact that we made some choices…" Mary's financial privilege allowed her to be a consistent care provider for her mother (a concern she had with the Home Care Program). However, a gatekeeping feature of the paneling process is a relationship with the Home Care Program; by avoiding having her mother involved in the program, her mother was not known to them, and thus couldn't be paneled when she should have been (i.e. exceeded over the equivalent of 55 hours of paid care per week). Service providers' comments reflected an acknowledgement that the system only knows those who are involved in the system. A system that is geared to treat those who are assessed as being in need (or are deemed sick), and not to keep people healthy. Mary's choice to limit her home care involvement and provide care herself resulted in a delayed assessments and eventual paneling for PCH placement with an extended wait in community.

Service providers expressed moralized beliefs about families and the care decisions that they made, for instance, implicitly invoking ideas about good and bad family caregivers. These designations were in part linked to assessments of the caregiver skill in acting as an intermediary between the care recipients interactions with the surrounding health care system, and the home care system. One participant stated: “it’s easy to put caregivers into groups, these are the ‘great’ ones because they go to all their appointments and they are always keeping us up to date. And when caregivers are not necessarily doing the things that we think of that would be ideal, sometimes we admonish them for that without understanding, well why is this happening.” These types of values-based judgements are rooted in a cursory view of caregivers’ work and relationship with the client and are reflective of the expectations service providers have for the care work caregivers should be supplying. Another service provider acknowledged, however, the pressures on families: “it almost feels like sometimes I’m threatening families that if they don’t put a plan in place our system doesn’t respond very well to emergencies.” Service providers judgements of caregivers also appear to be based on perceptions of caregivers’ ability to successfully navigate the system, while keeping coordinators updated on their progress along the way. It is unclear whether or how such assessments of caregivers affected the services case coordinators offered clients and families.

Although caregivers such as Mary were often tasked with making decisions on behalf of the care recipient, frequently their decisions were in part based on personal considerations – most notably those related to their care load. This often manifested in choice of location for housing for the care recipient, how far away the location was for caregivers and so on. Mary expressed worry that she was making choices that were best for her and not necessarily her mom, “based on the shortness of the commute,” keeping her mother in the assisted living facility longer than might be needed was in part due to a “kind of cost benefit” consideration. Based on her knowledge of the supportive housing care environment, Mary believed, based on her own research into the continuum of care system, conversing with other caregivers, and speaking with her mother's Home Care Case Coordinator, that she could provide the same if not better care that was offered to her mother in the supportive housing facility, while her mother resided in community waiting for PCH placement.

For co-residing caregivers, costs associated with co-residency extend beyond the financial realm. Existing research has demonstrated that providing co-resident care is associated with a higher mental and emotional impact (Elliot, Burgio, & DeCoster, 2010). Melanie's mother, like Mary's, was not assessed at a level of care that would make her eligible for paneling for a PCH; however, Melanie was not in the financial situation to be able to hire private care or provide care herself. In addition, since Melanie's mom co-resided, any additional private or public sources of care would increase the considerable stress she was experiencing. For instance, she described the revolving door of home care workers in her house (at times up to 6 different workers a day) as intrusive. Although Melanie also spoke of the cost of co-resident caregiving on her personal life (time for her children) and emotional well-being, she believed that an increase in public home support would only make her life more miserable.

> The problem is you want to make [her] happy but when you start to sacrifice the best years of your life you'll just resent it you know. I try not to resent it too much but those were special years when my kids were little and I had revolving door homecare workers all the time… We're looking at at least six visits plus the laundry [a day] and it was a revolving door of people and we didn't … I just couldn't take any more strangers coming in and out of the house all day.

And yet, when Melanie brought these concerns to her mother's Home Care Case Coordinator, an increase in care hours was the only option presented as available through the publicly available Home Care Program. As Melanie's mother was not deemed by the coordinator as eligible for paneling, the other options available to her were to hire private care workers for her mother or enrol into the Self and Family Managed Care Program (which Melanie mentioned was never brought to her attention from the case coordinator). Care providers are expected to make informed decisions regarding care provision, but they are not always provided with adequate information or guidance to do this. Regarding this, Melanie was never informed of the SFMC program, despite complaints to the case coordinator about the inconsistency staff in her home. Melanie's situation illustrates how system reliance on families to keep their loved ones in the community (including co-residence) can come at a great personal cost for caregivers. Other research has indicated that caregiver burnout can result in an apathy and disinterest towards care provision and can ultimately negatively affect the quality of life of the caregiver, and in turn the care receiver (Schaufeli et al., 2008; Todaro-Franceshi, 2013). The costs of avoiding or delaying institutionalization are not only of a financial nature but can be mental, physical, social, and/or emotional (Schaufeli et al. 2008; Picot, Debanne, Namazi, & Wykle, 1997). Ultimately, when the system does not offer adequate supports for caregivers, available options are limited options. This could result in caregivers initiating the transition process.

The implementation of 'aging in place' policies is increasingly shifting the responsibility of facilitating care for older adults onto families. The primacy of health literacy and health social capital privileges "the centrality of information to carers' lives and represents information as fundamental to good care" (Dalmer 2018, 2). This also relies on caregivers to become empowered to make 'good' and 'informed' choices. The ability to successfully navigate the health care system thus does not fall on the system's ability to guide people through it, but on the caregivers' ability to teach themselves how to do it. Service providers largely conflated providing caregivers with more information with helping caregivers to become more informed; however, this mentality neglects the "resources, time, [and] emotional impacts" (Dalmer, 2018, p.g.18) this work has on caregivers.

This chapter provided an in-depth examination into family caregiver experiences of the pre-placement phase of the transition process into a personal care home. It explored the experiences of family caregivers while providing and managing care for older adults who were living in the community (independently, co-residing, or supportive housing). It highlights instances where choice and control were present (and not) during this phase. In Chapter 6, I will detail experiences with the next phase of transition, the panel phase.

Chapter 6: Panel/Transition Phase

In this chapter I present an in-depth examination into the placement phase of the transition process into a PCH. This phase focuses on specific processes and procedures involved in the transition into a PCH, the key feature of which is the panel application. As background, the ‘paneling’ process entails a) an application and assessment of care characteristics that determines the older adult’s level of dependency and b) the presentation of that application/assessment to a panel review board who determines whether facility placement (supportive housing, PCH, chronic care facility) or staying at home in the community is most appropriate. Paneling applications can be initiated from either community or hospital[21], but regardless of initial location, paneling is a necessary component of PCH admission. In most cases, individuals who are paneled for admission into a PCH have already been receiving service from the Home Care Program.

Typically, the Home Care Case Coordinator (after consultation with the individual, their family, and their health care team,) ‘makes the case’ for placement to the panel review board, who act as gatekeepers to publicly subsidized forms of housing. This board functions to keep those who are not deemed needing out, and only admit those who have no other option. The board consists of “physicians and staff from the Long Term Care Access Centre and Home Care”[22], whose knowledge of the older adult is only second-hand and mediated through existing documentation, such as the Application and Assessment form and the oral report of the Home Care Case Coordinator. As such, the Home Care Case Coordinator has a fair amount of power and control over the transition process, when this occurs from community.

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[21] This process has recently been changed in an attempt to better help caregivers navigate and avoid PCH placement from hospital, however this practice was common during the time of data collection.

[22] http://www.wrha.mb.ca/ltc/pch/paneling.php

As a gatekeeper to the panel process, the case coordinator needs to ensure that all community supports have been exhausted before submitting a case to panel. For instance, if more could be done in the community (see Chapter 5 for Mary, Melanie, and Lorraine's circumstance) the case coordinator might direct the caregiver/client to other alternatives (e.g., more home care hours, respite programs) rather than present the application to the panel review board. In contrast, from hospital, the decision to initiate a panel application is usually made by a doctor or hospital social worker with input from a care team (e.g., including occupational therapist, physiotherapist, and the doctor). Once the decision to panel is made, they refer the case to a Long Term Care Access Coordinator, who submits the case to the panel review board.

This chapter provides analysis on family caregivers' accounts of their experiences of the paneling phase in relation to service providers' accounts of assisting families during this phase (including those located within and outside of the WRHA system). Sub-themes identified in family caregivers' narratives about the paneling process include: failure to communicate: the mystery of the process, loss of control and lack of involvement, and navigating and advocating during the paneling process. Caregiver participants, who were at this point providing care for older adults in their own homes, supportive housing, or hospitals, commonly spoke of not fully understanding the process, as well as feeling left out of the decision-making. Such experiences, as noted by Nolan (1996) may have longer-term implications for the transition and adjustment process. More broadly, they signal the need for sociologically informed analyses to help understand why and how health systems generate these kinds of outcomes for families.

Examples of caregiver experiences below are interspersed with system narratives based on the analysis of service provider transcripts and publicly available descriptions of paneling and related system processes, analysed with attention to broader sociological contexts and interpretations.

FAILURE TO COMMUNICATE: THE MYSTERY OF THE PROCESS

As illustrated below, participants often spoke of the panel process as being confusing or unclear. They described a lack of readily available public information about how the process works (likewise for information shared by professionals), about who is involved and makes decisions, or about how facility waitlists are managed. My own review of their public material, confirmed that the WRHA provides minimal up-front information as to how to access personal care home services. They refer individuals in community to contact their Home Care Case Coordinator about whether a personal care home is the right option, or alternatively (if individuals do not have a case coordinator) to contact the Home Care Intake phone line. The WRHA website further states that people who may be in hospital will be referred to the Home Care Program, who will implement a care plan for when/if they are discharged from hospital[23]. If individuals are not able to return home, the LTCAC Care Coordinator can help them access appropriate housing and care options, including PCH.

Although the WRHA has a webpage specifically describing the Paneling Process[24], the link to this page is not clearly posted on related pages such as "Welcome to the Long Term Care Program", "Accessing Long Term Care", or "Personal Care Home Services." I was only able to access the Paneling Process webpage by specifically searching for "Paneling Process Winnipeg Regional Health Authority" in a web browser. While the page does provide information on how this process works, such as "what is panel", "what if the panel review board denies the

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[23] While in practice this process has recently changed with the implementation of the Priority Home program (a short-term (up to 90 days), transitional, intensive, and restorative service available to eligible individuals). The information the WRHA provides publicly has not been updated to reflect this change

[24] http://www.wrha.mb.ca/ltc/pch/paneling.php

application", and "how are wait lists managed", it is only easily accessible to those who know where to look, what they should be looking for.

In contrast (and perhaps in part as a result) most caregiver participants acquired tacit knowledge of how entrance into PCH worked, in particular the panel process, through word of mouth, from friends and acquaintances. Those who seemed to navigate this process well had prior medical backgrounds or system experience (e.g., had previously transitioned someone or worked within the system itself), and appeared to have higher financial, social and cultural health capital (Shim, 2010), and to be more comfortable asking or demanding for more (or better) services; they also tended to have higher expectations of the system. In contrast, other participants did not know what paneling was, or that it existed; others went through the paneling process and still expressed not understanding how it works. Caregiver participants in this study overall tended to have high socioeconomic status, as such there was under-representation of disadvantaged groups of carers. However, more burdensome transition experiences appeared to have been experienced by participants with lower levels of education (high school or bachelor's degree), and/or expressed high levels of caregiver stress and burden.

The WRHA Paneling Process site states that once the application for placement is approved by the Panel Review Board, "the individual's name is placed on the wait list for their preferred and/or alternate choice of PCH. Applications are forwarded to the PCH by the LTC Access Centre." The statement suggests that people are able to choose which PCH they will go to (this was not necessarily the case for families we spoke to). Service providers expressed there are often extensive wait times that older adults and family caregivers are faced with when waiting in community for their 'first choice' placement. The WRHA further states waitlists for PCH differ depending on the facility, and can vary from a few days to many years, and "if at any time an individual wants to change the choices or decides that he/she no longer wishes to move from the Home they are in, the PCH staff or Social Worker will assist the resident/family and notify the Long Term Care Access Centre.” This was seconded by service providers who expressed that that in many cases, families will change their first choice home for something with a shorter waitlist if caregiving becomes too burdensome in community. While this is presented as a choice, the ability to change your preferred PCH, choice is constrained when presented with either: i) maintaining care in community with growing care needs and burden , or ii) choosing an undesirable PCH. Alternatively, if an older adult has an emergent health issue and is hospitalized while waiting in community, they will be transferred to the first available PCH bed, with no attention paid to their first choice. In this they are privileging the priority of the system (discharging someone from an acute care bed) over the desires of the older adults and their caregivers. The caregiver participants that expressed placement in their first choice home noted these were often ‘lateral’ moves, after placement in an interim PCH that they then transitioned into their first choice from. Long waitlists and the push to discharge individuals from hospital to the first available bed can result in ‘lateral moves’ being an onerous and often long process.

The discourse of choice (discussed further in the next section) obscures the reality of wait times for entry into PCH, which may add to subsequent confusion over what appears as a mystifying process. For Tara, who is caring for her mom living in a supportive housing facility, paneling was mysterious:

> [She was told] We’re gonna have to look at paneling her. We’re going to put her on the panel list. I don’t think we heard anything more about that for 4 or 5 weeks. We had a meeting with the social worker at the hospital, but she seemed more concerned to get us to sign the paper that said that if she didn’t select the first home that was offered to her we would pick up the $200 a day cost for staying in the hospital. And it really didn’t deal with

> her needs and where she wanted to go. We never heard back from the choices [of facilities] that we gave…

Tara's mom was paneled from hospital after an extended stay. When it became evident that Tara's mom was unable to ever return home, the hospital social worker initiated the paneling process. Four to 5 weeks passed with no word from PCHs they had selected as acceptable, and Tara's mother was moved to an "overflow" ward to await placement. Tara's mom died in hospital waiting for a PCH placement. The discourse of choice, presented as where caregivers would choose to have their loved one to live their remaining years, obscures the fact that it responsibilizes the waiting process onto caregivers for choosing PCHs with long wait times. When caregivers are given the option to choose, such as Tara, and have these choices overlooked or missed, it can result in caregivers becoming disheartened with the system. Individualizing the problem of wait times onto the choices of PCH placement preference, and not a system that is unresponsive to familial wants and needs transforms the problem of long wait times a private trouble, and not a public issue. The health care system, organized to respond to acute care priorities (Havens, 1995), has not adjusted to the needs of the aging demographic.

Tara described meeting with the hospital social worker and feeling pressured to sign an agreement to accept the first available PCH bed when it was offered or face a $200 a day cost for her mom to remain in the hospital (until they accepted a bed offer elsewhere). Making the decision to transition a family member into a PCH is an experience fraught with difficult emotions such as guilt, shame, relief, and sadness (Reuss et al., 2005; Sussman and Dupuis, 2014; Rodgers, 1997). Tara's experience suggests that bureaucratic and managerial processes can add undue stress onto an already emotional situation. It also suggests that the system as it is currently designed can punish family caregivers for inadequacies in how the system is designed, through service charges in declining a placement that they believe is inadequate or unacceptable.

It also explicitly contradicts the emphasis on choice elsewhere in public materials, be clearly indicating that there is really only one ideal option.

The WRHA paneling website, though likely not easily accessible, does confirm that individuals paneled from hospital must accept the first bed offer or pay a fee of $200/day. Some service providers framed this fee as being in place, for instance, "because an option was presented, and [they] said no" (hospital navigator). In this sense it is presented more as a punishment, and perhaps a potential deterrent for non-compliant behaviour (first bed refusal). In addition, the WRHA site also informs individuals that hospitalized patients will start paying per diem rates[25] (the personal cost individuals must normally pay to reside in a PCH) to the hospital as of the date the panel decision is made, while they are waiting for PCH placement. As the length of time between panel date and bed offer is unpredictable, clients waiting in hospital are then paying for the same amount of care they were previously receiving at no personal cost. Alternatively, those who are waiting in community for PCH placement only start paying the per diem charge on the day they are admitted to the facility.

Lorraine, who provides care for her aunt (and husband), described an experience similar to Tara's with respect to extended periods of silence regarding placement when her aunt was paneled from hospital:

> Through most of that 6-week period there was no one that would tell me exactly where she was at (*on the panel wait list*). I think they just said she's in assessment. There was no glimmer of hope for me to think she may be [even] considered for a PCH – not until the very last days. **…** I did some phoning through the social worker suggesting that I needed to know and wanted to know because we were also paying for her apartment which was $2800 a month at *the assisted living facility*…. And I wanted to know before the next month rolled around because we did end up paying three months when she wasn't there. And they just kept saying to hold on…

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[25] $37.90 - $88.50 depending on the individual's net income (https://www.gov.mb.ca/health/pcs/docs/guide.pdf)

Indeed, after paneling was approved, caregiver participants often described extended gaps of time before receiving updates about to the status of their loved one on the PCH wait list. Lorraine paid over $8,000 for rent for assisted living for her aunt (who was in hospital) before knowing whether her aunt would be paneled directly from hospital or discharged home to await PCH placement. Service providers noted that this kind of experience was characteristic of and reflected the nature of the health care system. Once a panel application has been made, one service provider noted, for example: “when someone is shortlisted their application goes from the access centre to the actual home. So the home doesn’t know about your mom until she’s short listed. So there’s nothing to say other than she’s moving up on the waitlist.” However, Lorraine was not even told whether her aunt *could* be paneled from the hospital. As such she was faced with maintaining her aunt’s apartment while she waited to hear. Inconsistent, unclear, or a lack of communication can lead caregivers to feel alone in a system that is meant to support them through their caregiving endeavour. For Lorraine, the “uncoordinated, fragmented, bureaucratic, and often depersonalized” (Bookman & Harrington, 2007, pg. 1005), process resulted in a burden (financial and emotional) that left her disheartened with the system.

Caregivers are often relied upon to make decisions on behalf of older adults, however, making un- or mis-informed decisions places risk on the stability of care for older adults, and undue stress and worry onto caregivers (Hicks et al, 2012; Ceci and Purkis, 2009; Dellasega & Mastrian, 1995). This is particularly salient during the decision to initiate the admission process into PCH, which is already fraught with emotions. In situations such as these caregivers must help the older adult in hospital while also maintaining their foothold in community, including ongoing payments to maintain spaces and/or services which are temporarily not being used. Not knowing how long these spaces should be maintained is stressful, yet if a caregiver does not maintain the apartment or assisted living space for their loved one, and they become discharged, they face additional challenges. Long periods of silence during transitions also contributed to some caregivers' perceptions of being 'left out' of the process.

Interpretations of the paneling process as unclear and uncertain were not unique to family caregivers, as one service provider (a case coordinator) noted "there sort of is a middle person and sometimes you don't get that communication back from the Access Centre." This participant spoke of having to track down information to better inform clients/caregivers of their waitlist status. Inconsistency was also present across the system, with some case coordinators mentioning weekly office meeting with the panel review board, and others appearing to only meet monthly. Inconsistency and communication gaps such as these affect caregivers' ability to access clear and reliable information and can have negative consequences for their system navigation experiences. The fragmented and uncoordinated health care system can lead to gaps in information transmission between people within the system itself, this can have consequences for the information care providers are given.

Service providers that participated in this study noted that questions regarding older adults place on the waitlist were common. Responses to waitlist inquiries from families varied between service providers, with one service provider expressing that she tells families "it's like cream. You know it'll rise to the top eventually, but you just have to kind of be patient." Another, however, spoke of taking a more active role on behalf of clients and families: "[they will say] 'we really need to go' and so yeah absolutely I will advocate on behalf of the client to see whether we can get this client in a little sooner to their first choice if possible." However, this participant added, "sometimes these waitlists are so big there's nothing we can do." Though uncertainty during paneling overall in part reflects non-linear and unpredictable care trajectories for some older adults, it also stems from a siloed and uncoordinated health care system; this places caregivers and older adults in a state of limbo, not knowing what steps to take next. Although some caregivers noted that they were provided with vague statements from health care providers to "just hold on a little longer" during the waitlisting period, they expressed that even a glimmer of hope or rough estimate of a timeframe would have made the wait more bearable (as noted by Lorraine above). Knowing that they only had to maintain their current circumstances or level of care work for a relatively specified period would have helped them maintain caregiving if they were in community. Their sense of coherence, and expectations of the system were thus affected through the way in which they received and internalized information.

Caregivers also expressed that they were often left not knowing what to do or where to go, when questions to professionals about paneling went unanswered, or they were given unclear directions. While WRHA service providers acknowledged at times there could be a lack of clear direction from people within the system, they equated this to a lack of readily available, accurate information given out by other service providers. To these service providers, the confusion caregivers are experiencing was based on misconceptions on how the process worked and not having enough information. A private case manager, however, cited more deeply rooted issues:

> Number one people don't know where to go. Number two they often are presented with major barriers. Like everything has to come through the central intake line… and [caregivers] can't articulate their problem in words that the system will recognize. They don't speak the same language. And then I think they have to deal with the inconsistency across the system. You go to one office for help and then you go to another office and one office does that and the other office doesn't do that

To the private case manager, the issue is not about caregiver's ability to receive accurate information, but the system's ability to align with caregiver needs, as there is "no orientation to the system". Caregivers are thus expected to learn how to articulate their needs to the system, instead of the system responding and adapting to caregiver needs.

The private case manager further asserted that working outside of the public health care system means she can tell families "things that paid government staff cannot" (such as about workarounds in the system, or PCHs to avoid), implying that system professionals are more likely to provide information that serves to benefit and protect the health care system. Notably, however, the costs of a private case manager limit this important tacit knowledge to families who are able to afford it.

A lack of clear direction was also a complaint made by Daria regarding her caregiving experience. Her father was in an independent living facility, and over several months her interactions with system professionals left her confused and not knowing what to do next:

> They kept going, 'he might have to move from here'.. like 'there might have to be some other arrangements made'… Okay well then direct us; like should we be looking for places now? Are there wait lists for these places; like what if we get him on the wait list and then he's okay to stay here when his time is up? Like will he get bumped from that wait list? Will he get moved? What will happen? We had no idea. Later I found out that if dad had been paneled sooner then he might have had a better chance of getting into the home of his choice…and we're going okay but nobody told us that that's what we should do. The whole paneling piece is very, very confusing and when you should initiate that right. Do you initiate it as soon as you start to notice that he's getting confused and can't… he may have to leave the assisted living. Is that when you immediately start? Do you wait until it comes to a crisis and he gets into hospital? Is that the best time to start? In all honesty I'm not sure I even know now. I don't even know what advice I would necessarily give to someone now. After having been through it; cause you could be wasting your time looking at different PCHs. It could be a total waste of time

Daria's experience highlights how a lack of direction appeared to leave some families to struggle through the process on their own. The biomedicalized health care system individualizes care through reductionist principles that often leave caregivers feeling alone (Dalmer, 2018). Although professionals simply may not have the answers, they also do not have the time to engage with families in a helpful way. In this way, strategies employed by the health care system tend to be focused at the individual level in a one size fits all model, and not through broader structural changes (Dalmer, 2018). A strong sentiment from service providers was that they wanted to be able to do more for caregivers, but as one in particular noted, “big caseloads [don’t] allow us the time to help people as much as we would like.” In the context of a culture of health care scarcity and crisis, therefore, navigating the system is characterized as something that “families have to do on their own”.

Some service providers (within the WRHA) spoke directly to the dilemma of knowing when to panel older adults. Paneling too early can result in a loved one being admitted into a PCH when they may not necessarily require that level of care or run the risk of having their application denied. However, paneling too late can result in bed offers to less-than-ideal PCHs, or adverse effects to both the caregiver (burnout) or older adult (falls or hospitalizations). One service provider explained:

> So that’s my dilemma as a case coordinator... I tell people there will never be a good time for your mom to go into a nursing home. It’ll either be too early or too late. There will be no perfect time where the stars and moon align. You want to do it when it’s too early because mom’s not in crisis; you’re not in crisis, being overwhelmed with the caregiving because a health thing happened. [But then] the Long-term Care Access Centre says I’m not sure if this person is ready yet because we really want them to be ready to be in a nursing home within 2 to 4 months right. It might be too early for her. She’s too good. So yeah it’s a very big balancing act as to when. Sometimes I feel like I’m threatening people. Like your mom is at extreme risk. You guys need to do this or else you will have no choice which is terrible.

This particular service provider claimed to encourage families to panel early, information that was not provided to Daria, as too early transitions in PCH were, in her opinion, more ideal than too late. However, this service provider also expressed that encouraging families to do this came across as a threat to families that if they do not put a plan in place the system will do it for them. The system, however, does not respond well to emergencies and will dictate (from hospital) where someone is placed, i.e. the first available bed. Paneling early thus might provide caregivers more control over the process but could potentially result in the shortening of life-enriching months or years in the community for older adults. The health care system is rooted in a biomedical model, that privileges “medically related, medically supportive, and/or medically oriented services” (Dalmer, 2018, pg. 19). System processes are created with acute care system primacy in mind, in this, health care systems have been created to be unresponsive to the needs of older adults, forcing them to fit into the “medical model and organization of care” (Havens, 1995).

WRHA system navigators we spoke to explained that their roles were often to consistently to “listen to [caregivers,] validate [them] and help them through” the PCH transition process. They acknowledged that providing explanations of, and answering questions about, the process can still be helpful for families, even if they are not happy with the end result (e.g., a PCH they did not choose). The implementation of such roles suggests the system is responding to some level of family and client dissatisfaction with the existing process, in a way that still maintains the control of the health authority over the process.

Michelle, for example, lives in Winnipeg but provided care to her rurally-residing parents. After first providing care for her father (now deceased), currently Michelle cares for her mother, who transferred to a PCH from hospital. Michelle described becoming very disheartened with the health care system throughout her father’s transition process, as he had been placed in interim care 70 km away from his home town. In her interview she discussed her current concern with issues related to her mother’s placement. After being told by her community case coordinator that her mother would be paneled in November, she heard nothing until following up herself in December, at which point she learned her mom would not be paneled until January. She pressed the coordinator for a simple explanation for this delay, and ended up with an apology:

> I said to her okay help me understand why that didn’t happen? Well it’s gonna happen in January. No, that’s not the question I asked. Help me understand why it didn’t happen in November when you said it was… November to January is three months extra … I wouldn’t let her off the hook. I said you need to tell me why that didn’t happen? Finally,

> she had no explanation. She said I’m really sorry it didn’t happen. I think she phoned me the next day when she said it will happen mid-December… Now I’m starting to get nasty to people because before I trusted everybody…. I thought people got back to you. I thought they really cared... but you know they do care, it’s just they’re lost in that whole bureaucratic jungle themselves, carrying huge caseloads.

While service providers expressed that family members are welcome to sit in on the panel review board meetings, it appears as though Michelle was not informed of this, nor was she given the opportunity to be present. Feelings of exclusion throughout the paneling process may connected to lack of clear communication and information. Michelle’s unmet expectation that the system would care for her mom resulted in her feeling disheartened and disappointed when the system did not stay true to their word (i.e. when her mom was not paneled when she was told she would be). Caregiver sense of coherence, through their ability to cope, is affected when expectations of system performance is not matched with the reality of the experience (Fries, 2019). Michelle’s generalized trust in the system had eroded as a result of feeling excluded from key information about the status of her mother’s paneling. This was not unique to Michelle and was prominent across almost all descriptions of transitions into PCH, in some form.

The service providers we spoke to emphasized how important it was that caregivers trust them through this process, with one such provider suggesting, for example, that a lack of trust “affects our relationship. All of a sudden you’re dealing with very angry families.” However, service providers expressed that large caseloads and “new policies and processes and red tape for us to jump through in order to get anything done … just delays the process even further.” Moreover, system and workload pressures restrict their ability to allow caregivers the room to make choices. Caregiver participants at times described how this erosion of trust affected them negatively, causing them to take on more caregiving responsibilities to offset perceived system deficiencies.

The system was characterized by service providers as difficult to understand, and readily available information online or in distributed pamphlets was not believed to be always clear or accurate. Information available on WRHA and Manitoba Health’s website is generic, offering descriptions of services but no real information on how to navigate. Some service providers noted that the information they can access is outdated (yet caregivers rely on information from service providers to be accurate and up to date). Dalmer (2018) claims that “navigating and managing information on behalf of family members are especially complex and invisible forms of care work” (pg. 2). The reliance on caregivers to navigate systems is affected immensely when given outdated information they are expected to work with. At the broader level, caregivers’ experience provides a glimpse into the system that individualizes care and caregiving. An individual’s ability to cope or adjust to the stresses of caregiving is affected by their ability to absorb, comprehend, and use the information that is presented to them, as this information management is increasingly becoming a vital part of caregiving (Dalmer, 2018). However, when caregivers are faced with mis-information or what they interpret as failures from the system, their ability to successfully navigate is greatly affected. This is not recognized as the fault of the system that creates these situations and information, but an individualized failure of that caregiver to properly adapt.

LOSS OF CONTROL AND LACK OF INVOLVEMENT

Family caregivers need to feel secure and supported when caring for loved ones (Funk et al., 2009a) and positive transition experiences require a sense of perceived control and involvement (Arksey & Glendinning, 2006; Lee et al., 2013; Reuss et al., 2005). This did not seem to be the case for participants in this study throughout the transition phase, who often expressed they were on their own to navigate, others described decisions being made ‘to’ them and their loved one, and not ‘with’ them.

Caregiver participants often expressed a desire for more agency and control over the transition process and some characterized their experience as one of a lack of control or involvement. Feelings of powerlessness and uncertainty are a marker of poor quality transitions (Lee et al., 2013). Although long waits reinforced caregivers’ perceptions of isolation from the paneling process, participants also identified decisions that were made for them with little or no consultation. Assessments of older adults’ needs are often “expert driven, with health professionals…frequently taking the lead role” (Nolan & Dellasega, 2000, pg. 761). The transition assessment process thus offer primacy to medical, professional opinions. Family caregivers lack of involvement often resulted in feelings of being ignored or brushed aside throughout the process. There can exist a disconnect, or tension between expectations in communication with caregivers and the health care system. Interactions with the system can “distort and fragment” (Lo & Bahar, 2013, pg. 69), experiences. Biomedical approaches can result in the “over-reach and uncritical acceptable of the authority of … the medicalization of everyday life and the norm of physician dominance” (Lo & Bahar, 2013,pg. 69). This does not imply any ill-will or intentionality from the perspective of the physician, but an ingrained belief that a biomedicalized approach is best, without recognizing the relevance of caregivers life context (Lo & Bahar, 2013).

This was the case with Kelsey. The following excerpt describes her experiences providing care for her mother, who had been living in the community, and was admitted to a hospital to receive rehabilitative services. The intent, according to Kelsey, was temporary hospitalization into a “rehab ward” with an eventual discharge home; however, this was not the end result.

> So, they paneled her. They paneled her. I don’t think that she needed to go into a PCH. I wanted her to go into supportive housing. It’s sort of the intermediate step. It did not sit well with me that they just said no. She needs to be investigated. I tried and they just said no, she needs to go into a PCH. That’s the place where I didn’t push hard enough, I think. I think I didn’t. Anyways it’s history. You make decisions. So, she ended up paneled personal care.

Kelsey expressed frustration and resignation when this decision (with which she did not fully agree) was reached without her involvement. Choice, in this instance, was absent, with assessment and subsequent placement of Kelsey’s mom being dictated by health professionals. Kelsey believed that, with rehabilitation, her mother could have been brought home, or at least placed in supportive housing, and yet this option was not presented to them. Kelsey expressed distress and guilt about the placement and noted that her mother rapidly declined once being admitted into the PCH.

Lo & Behar (2013) contend “doctors’ biomedical framework reduces patient narratives to a set of abstract symptom presentations, which are in turn treated as the scientific basis of diagnosis and treatment options. This may lead to miscommunication, inappropriate treatment, or generally dysfunctional consultations” pg. 69). In this, physician perspectives on the importance of facility based care, could override caregiver perspectives over concerns on placement. It is possible in this case that a doctor’s lack of understanding of the continuum of housing options for older adults and perhaps even of eligibility for supportive housing and/or PCH played a role in this decision. One service provider we interviewed made an observation that is pertinent, although not referring to this specific case: “especially the physicians are quite opinionated about who they think needs to go to a care home but they don’t know the eligibility. They just don’t want them to go home [back to the community].” The primacy of medical opinions over caregivers’ assessments of their ability to maintain older adults in community highlights a pathogenic health care system that privileges professional perspectives (Dalmer, 2018).

Kelsey, like many caregivers, provided care for numerous people over time. At times this involved hands on care as well as offering knowledge and sharing her experience with friends, family, and acquaintances in similar circumstances. Kelsey also believed her cousin had been inappropriately paneled:

> I have a 65-year-old cousin who was diagnosed with cancer and has tumours on her brain and has sort of like a paralysis; like stroke type symptoms. And she’s been panelled and put in a locked down ward in a PCH… which is totally inappropriate. [This happened] just within the last month. [The hospital said they] needed the bed, and she’s young, her girls are young, her daughters. So, they don’t know the system. They don’t know what’s out there. They did the whole paneling. They did their three choices for PCHs but of course none of them are available so this is the temporary placement. But nobody knows how long it’s gonna be and nobody knows whether she’ll live long enough to need it.

A recent system emphasis on hospital discharge and filling available PCH beds quickly, at the cost of considerations of appropriate fit for the older adult, is a problematic policy direction from the family’s perspective. Kelsey expressed being frustrated and concerned that her cousin, whose condition does not necessitate admission into a locked ward, is now residing in one because, from her perspective, the hospital “needed the bed.” While this is only a temporary placement, the family were not told how long it would last. Since Kelsey’s cousins’ condition was causing her health to decline rapidly, the family was very worried that this would be where her cousin will spend her last days. Prioritizing acute care priorities needs is reflective of a system that is organized to “respond to acutely ill patients, by physicians and in general or acute care hospitals” (Havens, 1995, pg. 256). In this way, from Kelsey’s perspective, her cousin was discharged to serve the needs of the acute care system, and not her cousin. It is unclear whether this decision was made with system finances in mind, (i.e. cost of the acute care bed, or PCH bed left vacant), however what it is clear this decision, from Kelsey's perspective was not made with her cousin in mind.

Some service providers may lack control and professional autonomy in the context of the broader policies and practices structuring their work. As one service provider noted: "it's usually not in our control where someone goes for an alternate placement. So technically it could be anywhere that has a vacancy because we just need someone to not be using an acute care medical bed when they don't need it." The need to vacate hospital beds, motivated by concern for fiscal responsibility and optimizing patient flow, can at times result in inappropriate placements (as above). Placement decisions like this stem directly from the needs of the health care system, and in the above case was a decision made to Kelsey and her family, not with them. Other participants likewise noted feeling discouraged and disappointed by a health care system that did not take their concerns into consideration and made decisions without the input of families because it was what was best for the system.

PCHs vary in services offered, staffing, rooming arrangements, and reputation. The rising number of nursing home scandals circulating in public awareness (Lloyd et al., 2014; Armstrong & Daly, 2017), as well as the varying levels of quality of care amongst PCHs mean families being particularly wary about placing their loved ones in certain homes (see Melanie's example below). Yet when hospitals transfer individuals into a PCH, the first bed offer is often an interim bed – a temporary placement while they wait for a PCH of their choice. One service provider noted:

> These are large facilities that have mostly shared rooms and those aren't very popular with families and they're usually older facilities as well. Those ones generally are what we're using as what we call the alternate – kind of the stopover before the care home of choice. So those ones you can get in immediately whereas the other ones vary from probably the soonest is 3-6 months to our longest wait facility is probably about 3 years…

Caregivers are strongly encouraged, even coerced (as above), to take the first available bed and can then apply for a transition to a PCH of their choice; this obscures the fact that frequent moves are not only disruptive for families but can cause adverse health effects for older adults. Yet the current structure of paneling places families in a position of blame for not accepting what they deem to be inadequate living conditions for the older adult in need of care.

The speed with which caregivers felt they were asked to make key decisions compounded their perceived lack of control, especially when they were coerced to make particular choices. For example, Melanie is a co-resident caregiver with a spouse and two small children also at home. She became very disheartened with the personal costs of caregiving, particularly the loss of quality time with her young children. After her father-in-law unexpectedly (and in her view, potentially preventable) died in one particular PCH, Melanie's mother was now being paneled from community after a period of hospitalization. Melanie described being pressured to place her mother in that same PCH:

> The [PCH] called and said we're ready to take her; this was after just a few weeks [after] my father-in-law had just passed away. He had been in that care home and he'd been somewhat neglected before he passed away and it was too late. His infection took hold. So, we were not sure that we wanted to put her in that place, and I was under pressure to accept it or reject it within a day, and I said I can't. I just can't do it. So that pissed off the homecare case coordinator big time and she would never speak to me again…. Yeah, cause I turned down that bed and they kept bringing it up. The past few months it's like every time anybody looks at a record – why did they turn it down? Well my father-in-law was in there and we asked for a doctor and you guys kept saying wait a couple more days. His infection got too bad. He died.

Family caregivers are expected by care professionals to make quick yet informed decisions about transitions into PCHs – bed offers are rescinded after 48 hours. Turning down a bed offer is often not a viable option, as it may result in penalties for the family, as one service provider noted:

> Well you can turn [a bed offer] down but your name goes completely off the waitlist and you have to start the process all over again. But I can't say they turn it down and then two weeks later we panel her for... We really can't be doing that right. So I make sure the

> caregivers know even though the waitlist could be 2 to 4 months you have to be willing to accept a bed the day that I panel your mom.

As such, caregivers must be willing to accept the first available bed or risk the consequence of being moved to the bottom of the waitlist and trying to maintain care in the community. While Melanie wanted her mom placed, she did not want her going to that particular PCH because of her strong lack of trust – she believed they provided inadequate medical care to her late father-in-law. Although the decision to turn down the bed offer might from one perspective be interpreted as an individual choice, Melanie's experience highlights not only how, from her perspective, there was no other option, but how she was in fact penalized for making the 'wrong' choice, from a system perspective. Indeed, Ceci and Purkis (2009) contend that case managers "have varying degrees of tolerance for [caregiver] choices, but they seem to have only that one rather limited way to conceptualise these events" (pg. 202). In this instance, Melanie's issue would be interpreted as a private trouble, and not a systemic failure. Melanie believed that declining the bed offer led to being labelled as difficult and subsequently ignored by the Home Care Case Coordinator (the decline was mentioned by the coordinator every time she requested services, as if she had done something wrong or the bed was no longer needed). Yet from her perspective, she was simply acting as an advocate for her mother.

Melanie and other caregivers who believed that they were labelled as resistive or difficult expressed that their experiences and interactions with people in the system changed afterwards, and that they were treated differently. There is an increasing expectation being placed on caregivers by the system to provide care. This is evident through aging-at-home policies that place emphasis on older adults remaining in community for as long as possible. However, the often underfunded and understaffed community based system (i.e. Home Care), can create significant and dangerous gaps in care that caregivers, without proper training, resources, and supported are expected to manage (Bookman & Harrington, 2015).

Considerations of choice and control for family caregivers should also take into account that throughout paneling and beyond, family caregivers balance the wants and needs of the older adult with their own capacities and needs. This can create challenges where these wants and needs to not align well. For example, an older adult might refuse to move into a PCH, but the family caregiver can no longer help maintain the older adult in the community, even with formal supports. Service providers spoke of this in ways that tended to suggest the older adults were no longer able to realize the extent of their physical or mental decline. One service provider stated:

> When the caregiver and care receiver clash, what I feel it stems out of is when the client have the insight to recognize, doesn't see their own deficits or insists on taking care of things themselves, but in the meantime, for whatever reason, whether it is required or not, the client taking care of things themselves really sometimes means that the care*giver* is taking on more responsibility

Service providers also suggested, however, that ultimately the decisions are "up to the client… ultimately you want to think of the client. It's very rare they will agree or follow through with something they don't want to do." The principle of individual autonomy in care decision making (Hicks et al., 2012) thus may be weighed by professionals against family caregivers' ability to maintain or provide certain levels of care, but ultimately clients' goals take priority. When older adults do require or want assistance from their families in making placement decisions, however, caregivers have more involvement and control.

A requirement of entering a PCH appears to be enrollment in the Home Care Program. In part, this is because one of the existing Home Care Program indicators signalling the need for panelling is that a client has exceeded a maximum of 55 hours of publicly provided care a week.

The Home Care enrollment requirement was a concern for some caregivers, who wished to provide care solely on their own, or through hiring private home care workers. Mary expressed that she felt that she was being punished by not enrolling her mother in the public Home Care Program:

> What I find troubling is the requirement that I use services that I don't actually require in order to get to where we want to go [into a PCH]. So I have to use homecare. I don't think that we should be advantaged because we go outside the system if we choose to, either by paying someone else or doing it ourselves. But nor do I think, and here's the problem, that we should be disadvantaged for doing it. So far our experience is that to do it yourself has been detrimental to my mother's wellbeing in a perverse kind of way. It's been beneficial in the short term. Her days are better. It's detrimental in the longer term because it's taken us this much longer to get to the point of paneling. And again I don't think we should be rewarded for doing it. We're doing it because we've already been rewarded in some way materially or whatever. But it shouldn't be about how many homecare hours she uses. It should be about how much care she requires. It should be about her level of impairment and not how many strangers come in to do x, y, and z for her.

Mary acknowledged that her position of financial and material privilege has allowed for her to care for her mother in the community with private care assistance. However, she now believes that the system has to 'catch up' in order to determine whether her mother should be eligible for paneling, a situation which disadvantages her mother, who now must remain in community at risk while awaiting panel and subsequent placement. Within this health region, there is no clear option for clients or families who wish to remain outside of the public Home Care Program yet retain the possibility of entry into PCH. As such, the system tips the balance of control towards a fragmented pathogenic system that, from Mary's perspective, appears to ground decisions on levels of home care service, rather than client status.

While some caregivers were comfortable asking or demanding more from health care professionals (and Courtney, Kelsey, and Michelle all escalated their concerns to higher levels of government), these participants had what Shim (2010) refers to as cultural health capital, while only one participant had a medical background, all three had high net household incomes

($100,000+) and expressed confidence in their ability to advocate and navigate for their loved one. Other caregivers expressed resigned acceptance that this is just how the system worked, and/or that they had not known they could ask for more. Such resigned acceptance reflected feelings of powerlessness and lack of control, and dissatisfaction with decisions made by people in the system wherein families simply had to make do with what they were offered. Resigned acceptance was not unique to caregivers' experiences with the system. Often service providers spoke about having to work within confines of the system. One service provider noted "that this is what we're working with kind of thing".

Service providers often spoke of the priorities of the system, and as one system navigator expressed, system priorities lie in prioritizing placements from hospitals rather than community, to divert ALC patients out of hospitals[26]. This extends wait times for older adults seeking paneling from community, which creates an unintended ironic effect, because "they present to the hospital because [their condition has] deteriorated before they have a bed available" and because their family caregivers reach a stage of burnout. At which point the priority is discharge them from acute care system to the first available bed, which adds to the backlog. This results in a complex system with many moving parts that are not necessarily recognized as affecting each other but, in fact, create system congestion and longer wait times. Long-term funding models are dependent on bed occupancy (Sussman & Dupuis, 2012), facilities thus operate at or near capacity (Doupe et al., 2011) resulting in insufficient PCH spaces to allow for older adult and family choices during the process.

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[26] While efforts have been made to change this approach since data collection took place, through implementation of the Priority Home program, it is unclear how this change has truly affected caregiver experiences of transition and older adult into a PCH.

In sum, some caregiver participants noted a lack of choice and control when decisions were being made for or to them, and when their input and concerns were not acknowledged or understood by the system. Feeling excluded from the process in this way can erode trust in the system and those who work within it. While caregivers may lack the professional expertise to inform decisions about institutionalization and paneling, the pathogenic health care system prioritizes medical perspectives over caregiver assessments. Families' choices are often limited to whether or not to accept a bed offer, in which case real choice is absent. Despite efforts to become more patient-centred, the lack of control and choice throughout the paneling process is reflective of a system that places priority on the system, and not the patient. The health care system, based on a biomedical, pathogenic, understanding of health and care is disempowering to family carers. The system relies on the work of care givers to keep older adults in community and out of hospitals and institutions, caregivers are told this is what successfully caring entails through the rhetoric of successful aging, and yet the system contributes to the ways in which caregivers cannot meet these expectations.

NAVIGATING AND ADVOCATING DURING THE PANELING PROCESS

Consistent with the original project in which this data originates, navigation was defined as accessing any of a wide variety of health and/or social services, supplies, and resources for the older adult, but could also include the work involved in ongoing monitoring and coordination once services were initially accessed. As learning and accessing information was touched on earlier in the first sub-theme, this theme focuses on all other forms of navigational work. Difficulties caregivers experience with the transition process are exacerbated within a health care system that is fragmented, with a lack of communication between systems. One service provided explained: “[the system] can be quite fragmented, [each system has] different criteria, and often the systems are designed [so] that you have somebody in my role of authority and you can't pass go until you've spoken to me, we've made them with these checks and balances which turn out to be a little less user friendly". The system is designed with many barriers and hurdles that prohibit access unless certain assessed needs are met. This bureaucratic complexity and fragmentation results in increased "structural burden for carers by requiring increasing levels of navigational work, and making the nature of navigational work increasingly challenging" (Funk et al., 2017, 6).

In many ways, family caregivers of older adults become "information mediaries" who are required to "seek information … on behalf (or because) of others without necessarily being asked to do so" (Dalmer, 2018, pg. 4). This work, as well as the myriad of other tasks involved in navigating the paneling process, is often invisible. Some participants expressed frustration over the navigation that is required during paneling; work they characterized as connected to how the system is designed. Moreover, even if one does all this work, positive outcomes are not guaranteed, as with Courtney, who provided care for both parents. She expressed that they "did everything they were supposed to do" during her father's transition, and yet still had significant challenges with paneling.

> We paneled him from the community. He was at home. We really wanted *PCH 1* where mom was. But they said that's the home that has the longest waiting list – five years plus. We had [hired] somebody at nights for him, seven nights a week, five from homecare and then we provided two nights. And then we had housekeeping. We had bathing. And then we had hired privately for 12 hours a day on top of that, plus us being there. … We were there all the time and we knew he wouldn't be there very long. He's waiting to go to *PCH 2* and he's quite high up on the list cause he's been paneled already. So, it won't be very long; but they couldn't tell us how long it would be. We were waiting our turn. But we kept noticing you know he was next on the list to go to *PCH 2* and you know you're watching like a vulture at the obits – oh somebody died at *PCH 2*. There's a bed. And you'd call and say… yeah but we can't give it to your dad because we've been told by the Region that we have to take in an emergency placement. Well there were nine or twelve of those and he's the next person to go in the bed, but people are getting in from other aspects. And you're saying well what's the point of entry? How do people get in? We're

> confused. He's next, but you're taking all these people? Oh yes, if he's shortlisted, they can take whoever they want and if there's an emergency placement in any of the hospitals, which there always is, then those people will go first, which means he will never get there.

In particular, navigating the paneling process for Courtney and her family required the coordination and administrative work involved organizing public home care, private home care, a rotating schedule of family members to check in on and be present with him, as well as keeping in contact with their desired PCH. "Being patient" and waiting their turn (as professionals often instruct) obscured the underlying, ongoing stress as Courtney and her family strove to maintain her father at home. Courtney understood the 'first available bed' discharge policy of hospitals to have affected her father's placement into his preferred PCH, and service providers in this study confirmed extended periods of waiting faced by caregivers who panel from the community due to priority being given to patients being discharged from hospital. In the broader context, this represents preference being given to the acute care system, discharging out of "costly and high-tech institutions, such as hospitals," (Fries, 2019, pg. 7), as a priority of those waiting in community.

Courtney was one of three participants in our study who escalated concerns to higher levels of government (beyond Home Care or Hospital) within the long-term care system. Such advocating forms another part of the navigation process for many family caregivers. Courtney described the response they received from someone at the Minister of Health's office:

> They basically told us why don't you take him home and then just run him to Emerg and we'll place him as an emergency placement. I said because that's not right and that's really hard on him. So why would I do that to him because your system is broken, and you don't want to have rules in place that everybody has to follow. So, we said no we're not gonna do that

Courtney expressed frustration regarding this and similar interactions, because from her perspective, they had followed the rules, and were waiting their turn, but were constantly being overlooked or forgotten. Hearing this advice indicated to her that their own efforts to follow the rules of the system might be undermined by those who circumvented these rules. It also concerned her that a government employee would make this suggestion – to leave her father in an emergency department and refuse to take him home[27], as a bypass through the system. Her trust in the system was further eroded.

Fragmentation of the health care system and resource constraints (heavy workloads) were indirectly implicated in caregiver participants' accounts of a lack of communication of key information between health care professionals, and between health care professionals and family caregivers. Tracey was providing care for her mother, who had been paneled from the hospital. While Tracey characterized her paneling experience as relatively easy to manage, she described her surprise and disappointment when she met all of the professionals who attended the panel meeting (e.g., doctor, social worker, occupational therapist, and physiotherapist):

> When we had a meeting about the paneling and we had a family meeting with all of the social worker and all of the various people who were involved – I realized that all of these people could have been there to help me the other times my mom was in the hospital. But I didn't know that. [Previously when her mom had been admitted to the hospital] there were huge issues trying to get communication going. If I had known I could have gone down to the social work department and they would have actually helped me…

Having discovered the full extent of (what was presented to her as) the care team, Tracey believed her mother's placement could have been delayed if these professionals had been engaged sooner (or if their assistance had been visible to and/or offered to her). As such, Tracey wished *she had known where to go, earlier*. Other caregivers expressed similar sentiments. Not knowing important information about resources and supports is reflective of the siloed nature of

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[27] Older adults are more prone to adverse health events when in emergency departments (Grunier, Silver & Rochon, 2011). As such, relying on emergency department, and subsequently hospital admission to advance personal care home placement is concerning regarding "the health system's ability to meet the needs of older adults" (Grunier et al., 2011, pg. 146).

the health care system and difficulties in “cross-institutional communication” (Bookman & Harrington, 2007, pg.1012). This relies on family caregivers to become information mediaries, and responsibilizes them to ensure proper communication and flow of information.

Providing care for multiple care recipients at the same time within differing systems could at times contribute to even more navigational confusion. Heather, for example, provided care for both her grandparents and mother. She describes her attempts to have her grandmother paneled:

> I went to three interviews for homecare for trying to get the paneling done where they told me that she’s now in the hospital and it’s now the hospital’s jurisdiction because if she’s in there for more than 30 days she’s no longer under homecare. And I’m like so well what happens if she gets released and a couple days later….? Well then, we’d have to re-pick her up and she would just have to be re-assessed and paneled when there’s time. So, there was a lot of back and forth of responsibility. [She] ended up in the hospital; put it on hold. And then went home for a few days, there was talk of it, and then had a second fall and ended up in the hospital. So, then it was on hold in the interim until her health got better and they knew they were gonna keep her in the hospital. And so, we thought she was going in for two or three weeks. And it ended up being three or four months. But then the hospital would not do any types of assessment once she was considered under their umbrella, until she was medically stable. Just when I felt like I was starting to understand how the system worked and how to get the people that I needed to help me in the different program areas; then we were now transitioning into how do I work within the hospital system. And they’re working together but neither of them are assuming responsibility for her. So, it was a real catch up because the hospital is a completely different system and they had social workers as opposed to care case workers. And dealing with a social worker for my grandmother and my grandfather at the same time. So, they each had a different social worker when they were in the hospital. So now instead of just dealing with homecare where she was responsible for both my grandparents, now I was dealing with two separate caseworkers.

Heather, the youngest of the participants at age 32, had stepped into the caregiving role when her mother was diagnosed with cancer. She expressed being overwhelmed at times with the different systems and processes including those regarding paneling from community versus hospital. Heather further expressed that “there are not a lot of systems there to help you. You have to be self-motivated and you need to know people that have either done it or been through it.”

Individual caregivers' familiarity with the system was also noted by service providers as a factor that contributed to caregiver's success in navigation. However, some caregivers suggested that changes in the way the system works, and/or changes in the needs of care recipients create unique transition experiences, such that prior experience was not always helpful.

The way in which the health care system has been organized (i.e. a conglomerate of differing programs and systems with varying levels of integration) has resulted in a situation where individuals with higher levels of cultural health capital can navigate the system with more ease. Caregivers who are "educated consumers" (as one service provider referred) require less navigational support, as "they [know where] they want to go and where they don't want to go". In addition, educated consumers have the skills necessary to problem solve, and advocate when interacting with the health care system. Caregiver sense of coherence is integral to their ability to effectively cope with the increasing demands of the health care system, however when they are consistently met with barriers that bar or delay access to supports, it affects the way in which they are able to navigate.

The requirement of caregivers to be "educated consumers" to better navigate the system presupposes that caregivers are required to have particular skills before they embark on caregiving. The health care system offers no orientation session to the ways in with the system works. Caregivers often expressed the need to triangulate information from multiple sources. This included knowledge acquired from service providers, their own research into the system, and tacit knowledge of the way the system worked from discussions with other caregivers going through a similar process. The need to triangulate information to successfully navigate both paneling and the transition into long term care was expressed by almost all participants. Caregivers activated their own personal networks to gather such information. Linda, a caregiver who provided care for her mother, noted "there's not a lot of traffic on the extra mile" when it came to help navigating from the system itself. She used this adage as a way of explaining how there are not a lot of people who work in the system who are able to help you or explain how the process should work. She also explained that in her experience, service providers will rarely go out of their way to help you if you need it. While many service provider participants noted that they wished they could do more for families, they believed their large caseloads and bureaucratic red tape restricted their ability to do so. From these statements it is apparent that service providers are shifting blame from the individual level to a broader systemic level. This statement is inherently conflictual because the individuals are shifting blame to a system to which they are a part of. Transition navigation was largely viewed by caregivers as something they had to struggle through on their own, with piece-meal information from other caregivers, and a lack of system level supports; overall, this tended to lead to negative transition experiences.

This chapter presented analysis on family caregivers' accounts of the paneling phase of the transition process into a PCH. Service provider and public expressions of the process were presented in related to caregiver accounts. This phase focused on the specific processes and procedures involved in the transition into a PCH, the key feature of which is the panel process. This chapter highlights how the mystery surrounding the paneling process, a sense of loss of control and lack of involvement throughout the process, and instances of needing to advocate for loved ones during the paneling phase affected them. In Chapter 7, I will explore experiences with the post-placement phase of the transition process.

Chapter 7: Post-Placement Phase

In this chapter I will provide an in-depth examination into the third phase of my findings detailing family caregivers' experiences helping older family members transition into PCH – specifically here I discuss post-transition, after the older adult has moved. Transition experiences do not end upon PCH placement; family caregiver participants described how their roles and responsibilities shifted, as they tried to adjust and help their loved one to do so as well. In this way, the post placement phase seemed to be understood by caregiver participants themselves almost as an extension or continuation of the overall transition experience. Sub-themes identified in family caregivers' narratives during the post-placement phase include: the move: experiences of disruption and adjustment, assessing the PCH: interpretations and trust, and augmenting and supplementing care. Other research has identified how experiences of long-term care transitions are shaped by how the older adult and their caregivers perceive relocation in particular (Lee et al., 2013), and that experiences with pre-move processes have a potential ongoing impact on adjustment to long-term care placement (Sussman and Dupuis, 2012).

Family caregivers' post-placement experiences will be presented and discussed here alongside the analysis of selected service provider transcripts. Notably, most service providers mentioned contact ceasing with families once this transition occurred, suggesting that within paneling-related systems, families' post-placement experiences are generally not acknowledged as important. Home Care Case Coordinators described how their contact with caregivers and clients post-transition ceased, reflecting the divide between community based, and institutional based services. However, a select few service providers (in particular two interviewees in formal navigator roles with the WRHA) discussed following client's post-transition, while some case coordinators discussed changes in families' caregiving responsibilities post-transition.

In particular, system navigators indicated they continue to work with clients only if they have not been admitted into their first-choice home, in which they help initiate the steps required to move an individual laterally, i.e., across the system into the home of their choice. Alternatively, if clients have been placed into their first-choice home, but wish to move, they can contact their system navigator and can start the PCH move process. However, at the time these data were collected, the system navigator positions were only just being introduced within the WRHA, with few people having access to these supports. Those without access to a system navigator must initiate lateral post-placement moves through general intake at the Long Term Care Access Centre.

After placement, some family caregiver participants expressed a sense of loss related to their shift in care role, as well as feelings of guilt or shame – depending on their feelings of whether they had somehow failed their family member, or for simply feeling relieved that the responsibility for personal care was no longer their own. Perhaps in part to mitigate such feelings, as well as in response to the lack of attention to social and relational needs (even, at times, physical needs) in PCH settings, participants often expressed strong continued feelings of responsibility for their family member – in particular for their social life and emotional well-being. Ironically, however, it can become even harder for caregivers to fulfil this sense of responsibility post placement. For older adults from rural communities, for instance, the closest available PCH beds can sometimes be far away from their families and support systems.

These and related findings are presented below and discussed within three post-placement sub-themes: caregivers' feelings about PCH placement, assessing the PCH: interpretations and trust, and changes in the caregiving role. The findings are analyzed within a broader sociological lens that connects these individual experiences to broader structures of care, responsibilization and familialism.

THE MOVE: EXPERIENCES OF DISRUPTION AND ADJUSTMENT

When an older adult moves into a PCH it can be a stressful and even traumatic for family caregivers, even as it paradoxically might bring some relief from burnout and some peace of mind. Although this transition is something that many caregivers actively worked towards and expected for many months or years (particularly when moves were made from community), the move itself tends to happen quickly and with little advance warning. Caregivers often have less than 48 hours to accept a bed offer and move their loved one into the facility or they forfeit the offer, regardless of circumstances (e.g. needing to book time off of work, travel into town, etc.). In part for this reason, many participants in this study characterized the PCH move as unpleasant for both them and their loved ones; this was compounded by a lack of staff available to answer questions or provide information during admission. The system also implicitly expects older adults to have family member available that can drop all other obligations to move the person into PCH and help them settle in. One service provider expressed that there is also variation between PCHs in the extent to which they assist families through preparing and inform caregivers of the steps involved in the moving process. The broader context is one in which PCHs are not held accountable, in existing legislation or accreditation and financing procedures, for supporting families and residents in this way. Despite this, long-term care is increasingly relying on the work of caregivers to perform throughout, not only the move-in phase, but subsequent social-emotional and at times physical care (Barken et al., 2016, pg. 321). PCHs are usually only held accountable for grievous incidents or complaints resulting in the death of a resident.

Paige, whose mother was transferred into a PCH after being hospitalized for several months, described one of her first experiences:

> So, I brought over clothes for her and I brought bedding and her own pillows and her own pillow cases and some of her personal affects and did her room up. And she was so happy, and she comes into her little room – "Oh this feels like home. This is great." And right away everything is gone. It's gone for labelling and then it's gone to labelling for a week. And so, it felt kind of unsettling. If I could have brought it in a few days earlier and had it labelled and all ready for her but I didn't know to do that and there was no opportunity because it's such a short turn around. If they would have given me the labels, I could have sewn them on or stuck them on but... I felt kind of bad for her cause all of a sudden, she felt right at home and then she was lost again.

Home and home-like environments are viewed as important for one's overall sense of wellbeing and identity (Brownie, Horstmanshof & Garbutt, 2014), and family members perform important activities in transforming, within constraints, the PCH space, for instance adding personalized touches to residents' rooms, or maintaining continuity of clothing and valued possessions. Choice in clothing, and the need for ontological order, is important for people. Simple changes like providing time for families to bring in clothing to be labelled pre-move would make moves easier, and less stressful on both caregivers and older adults. In PCHs the power to individualize rooms and belongings "is radically diminished…the physical space takes on a less homelike appearance with one's personal space appended to corridors that may contain medical apparatus and communal areas for recreation and dining" (Brownie et al., 2014, pg. 1655). That Paige's mother had to move quickly into the PCH with little advance notice is directly connected to broader structural constraints in which beds are expected to be filled as quick as possible, even though this not only inconveniences but disrupts and troubles the new residents and their families (in this case, it meant Paige was not provided with important information about labelling, prior to the move, and could not prepare adequately).

This was also the experience of Leanne who assisted her mother with multiple moves into PCHs. First from an interim placement to her eventual PCH, and then moves within rooms in the PCH itself. She expressed being told: “[the PCH] realized she needed more care than what they could provide on that end”, and that her mother was moved from one wing of the facility to another. Leanne provided the following response about the process:

> [It was] extremely, extremely stressful and it was stressful for the staff and it was stressful for me cause we had no choice. We had to move her room around and we had to get another chair…I mean we agreed why, but in the end if we didn’t agree to it we’d still have to do it anyway. So we had to get my mom to buy in ad that was a lot of major stuff to deal with all at once. It was a complete nightmare.

Leanne expressed that the lack of choice involved in the move was stressful for herself, her mother, and the staff of the facilities. She explained that this required negotiating and bargaining with her mother to accept the move as the space and layout of the room she had become familiar with was now being changed. Leanne was upset about this as: “no one had talked to me. We weren’t able to kind of prepare my mom. They just started moving her furniture out.” PCHs have different layouts, and they can, at times, minimize the space that older adults have to move in familiar pieces of furniture and memorabilia to be able to maximize occupancy. This example, broadly speaking, highlights how a lack or failure of communication across the system (in this case regarding the level of care Leanne’s mom required) has negative impacts on older adults and their caregivers who have to deal with the ramifications. It also highlights how the work that families partake in, and the choice and control families have in, ensuring older adults comfort through individualized rooms and belongings can be greatly affected through pressures to move, and a lack of communication about the process.

Disruptions related to clients’ familiar routines and belongings, while being inconsequential for the PCH, can be quite challenging, especially for older adults with cognitive impairment, and for the family caregivers trying to help them during a move. Likewise, suggestions made to caregivers to limit personal belongings that are brought in (due to perceived risk of theft, or damage) have implications for resident adjustment as well as family caregivers' abilities to help in this regard.

Long term care funding policies are dependent on bed occupancy, resulting in pressures on families to move in with limited time to organize and arrange for help, which helps PCHs maintain their occupancy levels (Sussman & Dupuis, 2012). When Michelle's mother was offered a PCH placement, she was given only two days to move her mother, and she was unable to do pre-packing to prepare (indeed, she had no idea even as to where her mother was on the waitlist). She elaborated:

> And then I get a call just in February and again we have a bed and your mom is being admitted and you have two days to move her in here… I said well I can make it next Thursday and they said no we can't have a bed going empty. So, my mom is now in there. So now I'm cleaning out her apartment and I try to deal with all her personal possessions and that's where I am this weekend cleaning her apartment. So, it has been like 4 years of... in dealing with all that mental and emotional and my mom became very, very dependent on me and very, you know, the guilt? Oh, you're not coming this weekend?...I would say since October I went every weekend but if I said to my mom, I've been here every weekend. She'd say no you weren't. You haven't been here every weekend. It's like you're *never* here.

Michelle's comment not only touches on the stress of the move but highlights the salience of emotional support from family members after an older adult moves into a PCH. In this respect the emotional and mental energy required to provide unpaid family care in the community does not diminish after placement, but rather it shifts. Michelle feels guilty that she is not able to visit or spend enough time with her mother at the same time as her mother's cognition problems, alongside the shift in care setting, create additional demands on Michelle to support her mother through a difficult emotional time. Michelle's experience highlights some of the care management tasks required of family, which encompasses not addressing only the practical challenges of moving older adults into PCHs but also emotional ones.

Moving a loved one into a PCH is a time fraught with difficult and/or conflicting emotions that can be exacerbated when the necessity of quick moves are coupled with a lack of support upon entry. While the move into PCH signals a potential change in the type of work that caregivers provide, families continue to provide support for relatives, even throughout the move-in process itself.

ASSESSING THE PCH: INTERPRETATIONS AND TRUST

A sense of coherence, specifically the expectation that the PCH would provide safe care for their loved one, was expressed by most participants. These experiences are in opposition to the case of Courtney whose mother was admitted into a PCH. When Courtney's mothers' level of required care exceeded what they were able to provide in the community, she was placed into a home that had a short wait time, however she believed that this PCH was "mismanaged, [and] not meeting standards of care." Wait times for PCHs vary across the city, and as one system navigator indicated, those with shorter waitlists may be recommended to families of those older adults who are "really struggling and need "urgent" placement. What can be obscured in such recommendations is that PCHs with shorter waitlists are those with low demand, including typically older, larger facilities, usually with shared rooms. This is indicative of general unawareness of the precarious nature of care in private PCHs.

Courtney's negative evaluation of the care received by her mother in the PCH was informed by her personal expertise derived from employment within the health care system. She provided this example:

> When we tried to get the staff's attention staff didn't know what to do because they were all agency staff – none of their own staff. And just incident after incidents of other

> residents hurting others and what not. So, we decided we couldn't have this go on. We couldn't move her. We couldn't take her back home… So, we hired somebody 16 hours a day. We hired a number of people. Between ourselves, my cousin and the staff we hired, we stayed with her till she fell asleep anytime between 11:00 and 12:00 and then we were there at 7:00 in the morning so that she would have somebody with her.

Courtney was concerned about the risk of aggressive actions in other residents and the staff's limited ability to notice and/or respond appropriately to the threat of resident-to-resident violence. Courtney had helped both of her parents' transition into PCHs and referred to this as "the most stressful time in caring for someone." Courtney's mom resided in a for-profit facility, where care aides were contracted staff (i.e., they did not report to the facility but to the private agency with which the PCH contracted care workers from). Courtney's concern about this, coupled with concerns about the low staffing levels, made her worry that her mom was at risk there. As such, Courtney and her family chose to hire a private companion at a great personal cost to them, to watch over her mother, in a setting in which she arguably should be safe and have access to 24/7 care and supervision. This family opted to hire a private companion due to their inherent lack of trust on the PCH's ability to provide adequate care. The lack of trust was based on the constraints associated with a biomedicalized task based service provision that focuses on primarily on ensuring pathogenic care at the expense of social, emotional, and psychological care.

Often older adults are transitioned into a PCH as a "last resort," when all other attempts at care and support have been exhausted. When these placements are interpreted as inappropriate or unacceptable, such as in Courtney's case, caregivers can develop anxiety over placement decisions, and residents may struggle to adjust to their new homes, enhancing caregiver stress (Reuss et al., 2005). Caregivers who internalize the placement as their personal trouble might second-guess the placement decision or blame themselves instead of an institutional and structurally rooted lack of supports available within PCHs.

In sum, when older adults move into a PCH, families can face in a desperate situation, with 48 hours to move them and their possessions into setting that is not always interpreted as welcoming, or safe. However, by this point, families have few other options – aside from requesting a second, lateral move, which can also be risky for the older adult, or, for those families with financial means, hiring supplementary private services to supplement the basic level of care in this setting (even this can become viewed as a necessity in this context). These findings suggest family experiences are connected to broader structural contexts (PCH resourcing and organization) that individualize the problem of adjustment. Contract workers, who are not accountable to the facility but a separate hiring agency, can result in a lack of awareness of potential safety risks (Armstrong, & Armstrong, 2016a). This is reflective of a task-based pathogenic model of care provision within PCHs that is not reflective of the type of care required for older adults, i.e. lacking in emotional care.

CHANGES TO THE CAREGIVING ROLE

After the move into a PCH, caregivers often shift the nature of support they provide from a primary focus on personal care tasks and help with instrumental activities of daily living to a primary focus on emotional and social well-being (Keefe and Fancey, 2000); this is not because the latter was previously neglected, but because they now had more time to be able to attend to these aspects of well-being. Some caregiver participants in this study likewise expressed that it was not their level of care that changed, but rather how they viewed their role and responsibility, in relation to particular types of care, had changed. Leanne, for example, explained that she visits her mom in the PCH every second day, but is now finally able to simply spend time with her and "just be a family member" again, without being preoccupied with tasks such as laundry or shopping. This statement draws on a sense of opposition between 'family' and 'caregiver'. Caregivers that described these types of experiences tended to characterize the overall transition experiences more positively. Some caregivers mentioned a sense of role conflict in moving from a care receiver (daughter or son) to a caregiver. One caregiver expressed that she now felt that she had become the "mother" in their relationship. This role conflict described by caregivers, in our Western culture, is rooted in something broader, within what we socially understand women's work to be, as "women learn how to care at a young age, and often in their homes rather than in educational or work settings, caring is often considered an intrinsic feminine capacity" (Barken et al., 2016, pg. 326). The discourse of 'caregiving' has thus been centralized on the idea of 'caring for' and not 'caring about', which devalues the emotional support and relational work involved in caregiving.

In contrast, other caregivers spoke of continuity, extensions or even expansions to their caregiving roles post-placement. Paige, who is providing care for her mother who transitioned from hospital after a broken hip from a fall and a period of interim care, described frustration with the continuing level of care work that still occupies her work days, including time spent on the phone navigating and advocating for her mother. For instance, she has found that she still has to relay information between health care providers post-placement. Some long-term care policies emphasize the rhetoric of "partnerships" with families, including being actively involved in making decisions. And although family involvement in various care tasks, is not necessarily explicitly condoned, in practice it can be both encouraged and assumed (Barken et al., 2016), especially in short-staffed, non-unionized facilities. The institutionalization of this expectation in practice can place undue stress and work on families to relay information should the health care system fail to do so. Family caregivers are thus responsibilized in ensuring the continuity of care for their loved ones. Paige provided the following example of her own frustration in relation to administrative aspects of care:

> She's supposed to be on some walking program. She was in one at *Interim PCH* and so she was supposed to resume that here and she's been there since *date* and I still haven't been able to connect with the occupational therapist that's supposed to be walking with her and I've asked the social worker and I've asked the nurse and nobody seems to know what's going on. Well who's accountable? And yet it has a very good reputation. It doesn't have a bad reputation at all. Everybody thinks it's a good place, but I do find that kind of slack really.

Paige believed this information should have been transferred from the interim care facility to the new PCH. She was particularly concerned because she was aware of the importance of prompt attention to mobility after a broken hip (e.g. the risk of permanently losing the ability to walk independently, transfer, or get up out of a chair). This is especially salient for older adults with impaired cognition, who might need more verbal prompting. Paige expressed she felt responsible for initiating her mother's walking program in her new PCH, but repeated unanswered calls and requests from within the PCH left her disheartened for her mother's potential to walk again. When systems operate in ways that impair the ability to transfer information and coordinate care between settings, this work is essentially offloaded, defaulting the responsibility for care management onto families. This can contribute to caregivers' feelings of guilt over inadequate care.

The unpaid labour and skills of family caregivers who provide supplementary care to older adults who reside in PCHs, though at times extensive, tends to be invisible (Barken et al., 2016). At the time of her interview, Patricia's mother had recently been placed into a PCH. She is unable to feed herself or effectively communicate. Patricia also described still needing to advocate for and provide high levels of care for her mom:

> I'm always there for supper hour. So, I will feed her. I will ensure she's changed for the evening then; ensure that she has all of the normal, I would say, activities of daily living that she would need for the next day, clothing laid out, teeth brushed, dentures clean. Glasses are washed and cleaned, hair is combed, anything of those nature then. I do spend if you want to just say some daughter time with her as well too. It just comes down to they've got so many to look after and they can't necessarily do that one on one care for an extended period. But they're always very, very grateful. They basically put my stool out and let me be ready for when I get there to be able to feed mom. They don't even bother starting now and I wish they would take a little bit more action around that, but I understand they've got you know eight other people that they've got to be able to look after as well during that dinner hour, relative to feeding and so they kind of just wait for me and away I go then. Mom is at a table of three. They sit at a table of four normally. And for that table I'm kind of the mother supervisor if you want to call it that. So not only do you help your mom, you help the other, in this case it's ladies, at the table too. It's just the fallout of that role that you play then. It's opening up their different food containers. It's ensuring that their tea bag isn't sitting in there for four hours. You know just helping them through their meal time too; then ensuring if there's spills that they're wiped up, But I also know that they are so pressed for their attention to others that are around the area that… yeah maybe I can't expect more than that then. And I've probably done it to myself too

Patricia supports her mother daily, such as brushing her teeth, and helping with dressing. Patricia's own explanation for this is that the low staffing and high workloads of the care home staff means her mother is at risk for inadequate attention. Indeed, family caregivers' continued involvement in a variety of types of care post-placement is often due to their concerns about inadequate staffing (Barken et al., 2016). In addition, Patricia explained how staff have started to assume that she will do this work (and she feels subtly shamed if she is not there); Patricia's care and concern for other residents also means she has started to feel obligated to help the other residents who are at the table when she is helping feed her own mother. Although she likes being helpful, Patricia expresses some resentment about becoming trapped into this role of the "mother supervisor." The care and tasks family perform become an integral part of the functioning of PCHs. This institutional reliance on Patricia and other caregivers in similar situations illustrates the shift from public to private responsibility for care work, and moreover "disadvantages residents with limited social support" (Barken et al., pg. 341).

Beyond supplementing the care and services that PCH staff provide residents, family care work for older adults in PCH extended beyond the facility. Courtney's father resided in a PCH, but due to the PCH's inability to accommodate his allergies, the family had to provide laundry services at home:

> So it's not just caring for him. We do his laundry cause he's allergic to the soap and the dryer sheets. So we have a number of loads of laundry that we have to do every week. Every facecloth, towel and every time you go to the bathroom they use another three facecloths and two towels. So it's eight to ten loads of laundry a week…

Courtney talked about how the way in which facility staff managed their time and tasks further exacerbated the laundry work required from her and her family:

> It's a hard thing to change their mindset from stripping the bed every time and using a different hand towel every time he goes to the bathroom. We were getting 60/80 towels a week. You know 8 sets of linens a week. And we're saying you know is there a reason? Well they wouldn't just straighten the bed. It was clean. It wasn't soiled. It's not wet. And yet they would just fold it up because it's sometimes easier just to do that right and throw it into the laundry. Well it's us doing the laundry. And we normally don't change the bed every day.

Courtney expressed that this additional care work took a toll on her family and their amount of spare time, noting "there isn't a lot of days where we're just a family unit and we're not running to the nursing home." Courtney's experience highlights how understaffing and facility policies can require families to perform housekeeping and ancillary work to maintain their health and wellbeing. Despite public assumptions about institutionalization as the end of task-based care responsibilities, the structure and operation of PCHs extend family caregiving careers "over time and across contexts" (Barken et al., 2016, pg. 340).

Paige, Patricia and Courtney's experiences indicate the potential for continued, if not potentially expanded, carer roles post placement. While participants themselves expressed feeling there was no other option for them in this context, their sense of obligation may be further informed by feelings of guilt about institutionalization and the need to reaffirm one's sense of purpose in the context of role loss (e.g., active construction of themselves as needed), alongside authentic concerns with staffing, and an acknowledgement of pressures experienced in interaction with PCH staff. Ultimately however, these caregivers emphasized they felt they had *no other choice* but to provide this level of/types of care. Visits to the PCH for caregivers like Paige, Patricia, and Courtney are not only about being just a family member again, but ensuring the emotional, mental, and physical well-being of their loved ones. Courtney elaborated on this in talking about her care for her father in PCH: "If you don't go as a family member to the nursing home your family member doesn't get the same level of care. It doesn't matter which nursing home it is. There isn't a level of engagement with the staff by family… your family member doesn't get the same amount of care." Courtney's example highlights how structural constraints, both in terms of staffing numbers and staff/resident engagement, contribute to her compulsion to extend extra time and effort.

These findings suggest that structural constraints shape and affect the relationships between caregivers and their family members. Particularly in terms of the public (i.e., paid) and private (i.e., unpaid) care work being undertaken (Barken et al., 2011). The system, through emphasizing task-based and time constrained forms of care and assistance in PCHs relies on family caregivers to supplement all other forms of care that may be lacking as a result. Biomedical models of care reduce individuals in relation to the kind of "medically related, medically support[ed], and/or medically oriented services" (Binney et al., 1990, pg. 762 as sited in Dalmer, 2018, pg. 19), that they may need. In this way aging is constructed as a medical problem to be managed, through a reductionist system based on pathogenic-specific services.

At the point of panel itself, caregivers were still expected to gather, assess, and utilize information, yet continued to experience a lack of control and involvement with the process, and felt compelled to advocate for their family member to ensure their needs were acknowledged and recognized. Choices between PCHs could be limited in practice, most notably for those paneled from hospital to the first available bed, and even more broadly for those paneling from community, as PCHs with shorter waitlists may be more undesirable, for instance typically older, larger facilities with shared rooms.

Caregivers who internalize inappropriate or unacceptable placements as their personal trouble might second-guess the placement decision or blame themselves instead of an institutional and structurally rooted lack of supports available within PCH. Families have few options besides requesting a lateral move – which can be risky for the older adult or families with financial means hiring supplementary private services to supplement the basic level of care. Choices continued to be constrained, as home and home like environments are viewed as important for one's overall sense of wellbeing and identity, yet, the power to individualize rooms and belongings in PCH settings is limited. Broader structural constraints, in which beds are expected to be filled as quick as possible, can inconvenience and disrupt new residents and their families. The system embeds an expectation that the older adult will have family members available that can drop all other obligations to suddenly move the person into PCH and help them settle in. These kinds of experiences are connected to broader structural contexts (resourcing, organization) to systems that do not recognize carer burden and/or that individualize the problem of 'adjustment' to PCH.

Moreover, although some long-term care policies emphasize the rhetoric of "partnerships" with families, including being actively involved in making decisions, staff and systems can come to rely upon certain forms of work from families of residents, both encouraging and assuming it. The institutionalization of this expectation in practice can place undue stress and work on families, and yet is maintained because caregivers believe there is no other choice, unless they want to put their loved one at risk (in a context of inadequate staffing). This can generate continued if not potentially expanded carer roles post placement, reinforcing expected caregiving roles in the lives of older adults as they transition into PCH.

This chapter presented analysis on family caregivers' accounts of the post-placement phase of the transition experience. As presented, transition experiences do not end upon PCH placement, the work and care provided extended the overall transition experience through experiences of disruption and adjustment, assessing the PCH, and augmenting and supplementing care. In Chapter 8, I present a summary of my findings in relation to broader sociological knowledge, discuss implications or research, theory, and policy/practice.

Chapter 8: Discussion

My initial goal in this thesis was to focus specifically on the paneling process, as it the key point at which someone is permitted (or denied) entry into a PCH. However, my analysis of caregiver transcripts led me to believe it is more productive to consider multiple points of contact within the system as influencing the experience of transition. This extends beyond an oversimplified conceptualization of transitions as about individual adjustment through set stages to address long-term system interactions as well as power and control across the continuum (Lee et al., 2013). For instance, one should consider how transition experiences can be extended if the first-bed PCH is not desired (i.e. lateral moves within homes). Since transition-related work did not end after placement, the post-placement phase can be viewed as an extension or continuation of the transition.

As such, the goals of this study were to understand: i) the experiences of family caregivers as they transition an older adult into a PCH (especially in regard to opportunities for choice and control), ii) service provider interpretations of this transition, and iii) publicly available representations of this transition. My analysis drew on 55 interviews from 22 different family members who were caring for an older adult at various parts of the PCH transition process, as well as 9 interviews with service providers who either worked within (WRHA employee) or outside of (private case manager and non-profit organization) the health care system in Winnipeg. This was supplemented by publicly available website information about the paneling process (see below).

Caregivers' activities and experiences during PCH transitions can be examined generally within three discrete aspects of the transition, albeit recognizing that care work activities shift and flux. As such, findings were organized according to three phases with associated sub-themes pertaining to caregiver experiences: (1) pre-placement (including experiences of circumstances that led to initiating PCH placement); (2) panel/transition (including experiences of panel and placement processes and procedures, including administrative work); and (3) post-placement (e.g., the move and settling in to the PCH and changing care roles).

The experiential sub-themes as presented in the previous chapters are:

1) Pre-placement phase
    i. Replacing and/or supplementing care
    ii. Assumptions about family care (not being recognized or heard)
    iii. Additional work in avoiding or delaying institutionalization
2) Panel/Transition phase
    i. Inadequate information (the mystery of the process)
    ii. Loss of control and lack of involvement
    iii. Navigating and advocating during the paneling process
3) Post-placement phase
    i. The move: experiences of disruption and adjustment
    ii. Assessing the PCH: interpretation and trust
    iii. Augmenting and supplementing care

In this concluding chapter, I position these findings in relation to broader sociological knowledge and discuss implications for research, theory and policy/practice.

Thus far, I have explored the experience of family caregivers as they transitioned an older adult across the continuum of care, culminating in their eventual PCH placement, through thematic analysis of secondary qualitative data. Drawing primarily on caregivers' descriptions of interactions with the health care system, I analyzed their interpretations of the system as helping, hindering, or contributing to the transition process, as well as the ways in which choice and control appeared to manifest (or not) for families across the transition process. Throughout, caregiver experiences were juxtaposed against service provider accounts of navigating this transition, as well as publicly available descriptions of the process on government and regional health authority websites (material available through WRHA, Manitoba Health, and the Long Term & Continuing Care Association of Manitoba).

ANALYTIC SUMMARY OF FINDINGS

Transition Related Challenges.

Although many family caregivers tended to detail difficult transition experiences, this may have been influenced by the recruitment methods for the study – which asked for caregivers willing and interested in speaking about system navigation. However, participation was not dependent on negative or overly complicated transitions. The findings from this analysis illuminate the complex experience of a PCH transition from the perspective of family members, and in particular, highlight the navigational or information work[28] they perform, and the structural burden they can face throughout the process (Lilly et al., 2011; Purkis & Ceci, 2015; Funk et al., 2017). Caregivers spoke of challenges spanning the transition into PCH that touched on many types and many aspects of system interactions, including their access to resources, supports, and information (Bookman & Harrington, 2007).

Indeed, a primary concern is the structurally generated sources of stress and burden, tied to work required of caregivers across the entire transition process (Lilly et al., 2011; Purkis & Ceci, 2015; Funk et al., 2017; Barken, Daly & Armstrong, 2016). This is best exemplified by a

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[28] Information work both informs and guides the care that caregivers have to partake in to facilitate care; it involves the steps required to seek out, evaluate, use, or share information (Dalmer, 2018).

lack of choice and control and self-directed information work throughout the process. In the pre-panel phase this included their work replacing and/or supplementing home care, connected to embedded assumptions about family care (that result in not being recognized or heard by the system), as caregivers sought to avoid or delay institutionalization (Bookman & Harrington, 2007; Sussman & Dupuis, 2012; Hainstock et al., 2017). In the panel phase this included managing the mystery of the process (e.g., through information work), system-induced loss of control and lack of involvement and having to navigate and advocate for older adults and for caregivers' own needs (Dalmer, 2017; Dalmer, 2018; Reuss et al, 2005). The system, as it currently operates, can effectively punish family caregivers for inadequacies in system design through service charges, and positioning on waitlists. Caregivers often must help family members in hospital while maintaining their life in community, including payments to maintain spaces and or services which are temporarily not being used (Sussman & Dupuis, 2012). Finally, after the move, carers manage the disruption involved to mitigate its effects on their loved one, while assessing PCHs for trustworthiness and adequacy of care, and augmenting and supplementing care within the PCH (Barken et al, 2016; Keefe & Fancey, 2000; Dellasega & Mastrian, 1995).

Feelings of frustration and hopelessness were exacerbated for caregivers who believed those working within the system did not see the constraints on their own lives that could limit their ability to provide care, and instead assumed that they could, would, and at times should provide care for their family member (Hainstock et al., 2016; Barken et al., 2016). This sentiment was especially evident among co-residing caregivers, who also expressed an added level of expectation from care recipients.

Caregivers also struggled with the temporal gap between requesting formal services, assessment of need, and service implementation (Bookman & Harrington, 2007; Armstrong & Armstrong, 2016). For instance, between 2012-2014 there was an average wait time of 37 days to receive a home care assessment (in the WRHA) and an average wait of 16 days after assessment to receive care (in the WRHA); this has been described as a significant 'disconnect' (Auditor General, 2015, 5). Caregivers expressed similar sentiments about the paneling-related wait-times, as well as concern for how this affected the quality of life of their loved one (Dellasega & Mastrian, 1995).

Struggles with navigational forms of care work in particular could complicate transitions between care settings (Funk et al, 2017). Though uncertainty about the paneling process can in part reflect a non-linear and unpredictable care trajectory, it also a by-product of a system that effectively responsibilizes individuals by tasking them with identifying and putting in place supports to facilitate the transition process. Successfully navigating the PCH transition can be onerous and time consuming, and requires cultural health capital (Shim, 2010; Collyer et al., 2015). Dalmer (2018) refers to this as reflecting the primacy of health literacy approaches which privilege "the centrality of information to carers' lives and represents information as fundamental to good care" (p.2). Yet navigation and information work are not necessarily an inherent part of care provision (especially in the presence of effective case management support), but represent caregiver responses to a fragmented system that places the onus on families to be informed and empowered and to responsibly navigate the transition for their loved one (Hainstock et al., 2016; Barken et al., 20116; Bookman & Harrington, 2007). Service providers in this study, for instance, often mentioned the need for family caregivers to be 'empowered' and become 'educated consumers.' In this context, not only does inconsistent or absent information affect caregivers’ abilities to access clear and reliable information, but the system serves to disadvantage those with lower socioeconomic status, and poor interpersonal skills (generating inequities), as well as older adults without a developed support network (Hainstock et al., 2016; Sussman & Dupuis, 2012; Dalmer, 2018).

Findings of navigational struggles is supported by a relatively recent growing body of qualitative research in several countries with similar models of health care systems to ours (Reuss et al., 2005; Sussman & Dupuis, 2012; Hainstock et al., 2016; Bookman & Harrington, 2005). Similarly, research on both older adults and their families tend to highlight dissatisfaction with the transition into PCH (Lee et al, 2016; Browine et al., 2014; Reed et al., 2003; Adekpedjou et al., 2018). My study both complements and adds to the area of literature through an interrogation of system gaps and barriers that result in navigational troubles. By understanding and examining specific sources of caregiver burden, targeted efforts can be made in system redesign to better serve older adults and their family caregivers.

My review of the transcripts paid particular attention to family and service provider narratives on similar topics and juxtaposed them with one another. Although family and caregiver narratives were related to the same topic, they were not in direct response to one another. Additionally, I considered the type and kind of information that was available to caregivers on the transition process. Comparing family experiences with service provider perspectives was intended to facilitate the exploration of where (and to some extent why) some personal experiences might contradict public and practice representations of the transition process. Prior to data analysis, my assumption based on the literature was that I would find explicit discrepancies between caregiver and service provider narratives. Data analysis indicates otherwise, revealing that discrepancies between were less pervasive than expected. Many service providers seemed to re-affirm the navigational struggles of family caregivers, or at least express awareness of the types of struggles family caregivers were having during transitions. Notably however, some service providers interpreted these challenges as resulting from issues with caregivers' individual abilities to navigate successfully, and not broader systemic or structural problems within the system. When systemic sources of navigational troubles were acknowledged, service providers tended to express resignation – that this was just the way the system work, and/or that their 'hands were tied' in their role, and they were unable to step in and do more for families who were struggling.

Transition-related difficulties manifest in additional time, effort, stress shifting onto family caregivers to organize appropriate care, and need to be viewed as embedded in the structure of the existing care system (Lilly et al., 2011; Bookman & Harrington, 2005; Purkis & Ceci, 2014; Funk et al., 2017). Broader tendencies to individualize family caregivers' navigational troubles as a private issue (e.g., inability to cope with the work necessary to provide care), ignores structural and organizational deficiencies in the health care system that contribute to these troubles, through shifting and/or generating more navigational and information work (Hainstock et al., 2016; Dalmer, 2018) onto families (via poor system function, gatekeepers between systems, bureaucratic policies, and incomplete or inconsistent communication: Funk et al., 2017).

Choice, Control and Power.

In contrast to the individualized interpretations of service providers, interpreting the findings from a sociologically informed perspective, and within a broader context – political, economic, historical – suggests that responsibilities for navigation work and care management are expanding for families, many of whom are at the limits of caregiving (Chappell & Penning, 2005; Hainstock et al., 2017; Armstrong & Armstrong, 2017; Havens, 1995). At no time did caregivers in the present study express that they could or would take on more if they needed or were provided the opportunity. Instead, they spoke of doing as much as they could, and yet feeling that it was still not enough (Nolan & Dellasega, 2000; Nordgren, 2010). In addition, in many situations caregivers had no other choice but to provide certain types or levels of care (Nordgren, 2010). Under the apparent guise of having the ability to choose (e.g., whether to provide care at home, or choice of PCH), in practice many structurally rooted factors affected their available options and constrained their choices. For instance, although aging in place programs and policies are often presented as allowing for more choices for older adults, underlying this is the downloading of costs (financial and otherwise) from the health care system onto older adults and their families (Armstrong & Daly, 2017), and the generation of additional navigation related work demands and stressors (Lilly et al., 2012).

Caregivers might also not be informed or allowed access to supportive programs or services or have to seek out their own information and solutions to problems that arise (Dalmer, 2018). Transition navigation was largely viewed by caregivers as something that they struggled with on their own with piece-meal information from other caregivers and a lack of system level supports (Reuss et al., 2005). These interpretations tended to be associated with caregiver experiences of having little choice or control over the process (Reuss et al., 2005; Dellasega & Mastrian, 1995). Feelings of powerlessness can be exacerbated within a health care system that offers primacy to medical and professional opinions over caregiver assessments (Nolan & Dellsega, 2000); this is particularly evident in the present study, in paneling-related decisions. Families' choices are often limited to whether or not to accept a bed offer. Broadly, the privileging of professional perspectives reflects a health system that is organized around medical dominance and a reactive, pathogenic perspective – oriented to treating a disease or illness or providing “sick care” (Segall & Fries, 2011; Fries, 2019).

Importantly, caregivers’ experiences – of the work required to fit into and navigate home care, of regimented, inflexible, task-based, and unreliable home care services, and of feeling ignored, contribute to feelings of being overwhelmed, and of burnout, ultimately constraining choice (Purkis & Ceci, 2015; Ceci & Purkis, 2009; Lilly et al., 2011). Specifically, such features figured prominently in some caregiver’s accounts of unsustainability and burden, and to deciding to start the PCH paneling process (Nolan & Dellasega, 2000). However, even then they can face constraints around whether or not the older adult is even eligible to be paneled, from a system perspective.

The culture of health scarcity and crisis, often predicated on an unfounded concern that the rising number of older adults will bankrupt the health care system (Bauer et al., 2003; Armstrong & Armstrong, 2016), can result in punitive actions by the system to “protect” itself, and navigating the system as something caregivers must do on their own (Minkler & Estes, 1999; Armstrong et al., 2001). The unfounded panic surrounding aging and the explicit focus on fiscal responsibility comes at the expense of a fulsome consideration of the diverse care needs of older adults and their care givers. Consequently, this contributes to the offloading of state responsibility on to the citizenry, particularly in relation to the financial, emotional, psychological and mental burdens associated with caregiving. Moreover, system priorities lie in PCH placements from hospitals, to divert ALC patients[29]; however, this extends wait times for older adults seeking paneling from community. And such long periods of silence or uncertainty,

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[29] The policy around paneling has changed since caregiver participants were interviewed, in an attempt to eliminate PCH paneling from hospital, through the implementation of programs such as Priority Home, and transitional care beds, however, it is unclear how this change has truly affected caregiver experiences of transitions

as noted above, further contribute to caregiver stress and perceptions of being left out of the process; these are associated with more negative transition experiences, as well as what appeared, among caregivers, to be a generalized distrust both the people who work within the system, but the health care system itself (Nord, 1996; Dalmer, 2018; Rodgers, 1997; Nolan & Dellasega, 2000). In the immediate, caregivers respond by taking on more responsibilities to offset system deficiencies, but more broadly, such dissatisfaction and distrust can result in a loss of support for public health (Barken et al., 2016; Bookman & Harrington, 2005).

The Broader Context: Towards A Sociological Interpretation.

The health care system and many of its programs and services were founded on acute care principles in a time of physician dominance, as well as lower average life expectancy and less extensive rates of chronic and co-morbid conditions (Havens, 1995; Armstrong & Armstrong, 2016). Care for older adults was largely expected to be a part of private home life, the responsibility of the family (in particular, women) (Armstrong & Armstrong, 2016; Bookman & Harrington, 2005). The implementation of the post-war welfare state, increasing numbers of women entering the paid workforce, and the spread of health promotion principles in Canada generated additional interest in non-medicalized, social programs to help keep older adults in the community (i.e. Home Care, which was introduced in Manitoba in 1974). The introduction of long-term care facilities, intended to reduce the number of specialized hospitals designed for rehabilitation, chronic care, and psychiatry, was done as cost-savings measure (Armstrong, 2011). However, over the last several decades, the expansion of neoliberal ideologies throughout health care systems, have effectively individualized the responsibility for care, navigational tasks and care management back on to individuals (along with cost-shifting) (Chappell, 1993 Armstrong & Armstrong, 2016; Segall & Fries, 2011). Home Care Programs increasingly are moving towards more task-based delivery that prioritizes fiscal responsibility over long-term social and preventive care and reflects an increased focus on “meeting primarily short-term and emergency needs” of clients (Funk, 2016, pg. 83) – this is largely driven by the broader needs of the more costly acute care system (Havens, 1995). This shift is also evident in health system policies that dictate service charges for those who remain in the hospital when medical professionals have determined they are no longer eligible, and first available PCH bed policies (Havens, 1995).

The health care ‘system’ (an organization of largely siloed programs and services) has thus not been organized, or priority made, to accommodate older adults living with chronic co-morbid conditions, or their families (Havens, 1995; Armstrong & Armstrong, 2016). Ageism and familialism[30] are institutionalized within these systems (Minkler & Estes, 1999; Armstrong et al., 2001). This is evident in legislation such as the *Canada Health Act* that only guarantees health system funding for emergent or hospital care and distinguishes home and residential (PCH) care as ‘extended health services’ (Rachilis, 2011; Armstrong & Armstrong, 2016). More broadly, many of the challenges encountered by family caregivers in this study reflect a system in which only the ‘sick’ can access publicly provided programs and services (i.e. day programs), or other health promoting activities that could ultimately mitigate further health care use or demand (Segall & Fries, 2011).

Aging in place policies generally align with successful aging discourse to emphasize how older adults should age in place, in that they remain in community free from disease and decline, as well as have a social support network of available family/friend caregivers to assist them in this regard. My research suggests that these policies and practices, in fact, have contributed to the

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[30] The presupposition that it is the family’s responsibility to provide care for people

unintended (and ironic) consequence of early transitions into PCH for some. This is especially true when caregivers are unsupported (through services and/or information) and left on their own to navigate the system. This can be attributed to structurally induced caregiver burnout that precipitates the PCH transition. While the system suggests that it is client-centred, during the transition process at least, it is the caregiver who is doing the bulk of the navigational work. Additionally, the illusion of choice, presented as though it is what older adults and caregivers want, in fact places a societal pressure onto older adults regarding how they should age, and caregivers regarding how they should facilitate care. While the system emphasizes choice, the reality is, choice is often limited to choices that benefit the system, and not choices that benefit older adults or their caregivers.

IMPLICATIONS OF FINDINGS

The emphasis in existing health research on transitions and older adults tends to focus primarily on moves between hospital and home (e.g., hospital discharge) (Gozalo et al., 2011; Giosa et al., 2014). I chose to focus my research on the transition experiences of family caregivers when they help an older adult navigate through the continuum of care, into a PCH. This research expands the body of research on care transitions and incorporates caregiver voices, which are key to understanding the transition experience more fully.

The transition into PCH is often precipitated when the care needs of the older adult exceed a family’s ability to care for them in the community (a symbolic ‘failure’ in relation to policy and rhetoric around successful aging and aging in place). My research thus explored the transition period for families, and their interactions with system processes that helped (or hindered) them during this difficult, often emotional time.

As there is limited research available on the structural processes and systems that shape caregivers' specific experiences and interpretations of the transition into PCH, my research provides unique insight into the forms of work caregivers perform during this time, as well as systemic gaps in the system which complicate and generate these forms of work. Although my findings confirm some of the existing literature on caregiver experiences throughout the transition into long term care (e.g., burden, stress, system navigation), (Reuss et al;., 2005; Sussman & Dupuis, 2012; Hainstock et al., 2016; Funk et al., 2017), my analysis contributes by providing a comprehensive, in-depth understanding of the transition process across a broader span of the transition, and employed critical gerontological and political economic perspectives (Armstrong et al., 2001; Armstrong & Armstrong, 2016; Minkler, 1999; Estes & Phillipson, 2007) to contextualize and provide broader, critically informed knowledge about the care management and information work that families are expected and relied upon to perform (Dalmer, 2018). Moreover, my research has highlighted not only the systemic origins of navigation-related burden, but demonstrated how, ironically, this can contribute to their decisions to institutionalize their loved ones.

Through engaging with critical gerontology, and by juxtaposing service provider accounts with those of caregivers, I was able to highlight how navigation-related challenges were often interpreted as a personal, or individualized problem by service providers (and even some caregivers), rather than gaps or problems within the system design itself. Such individualized interpretations reflect a broader context of neoliberalism as well as a pathogenic system in which health more broadly is also primarily positioned as an individual problem or responsibility, promoting dependency "on health care products and services" (Segall & Fries, 2011, pg. 27).

This resulted in caregivers experiencing structural burden, and resulted in feelings of guilt and shame failure, in relation to negative transition experiences (Reuss et al., 2005).

Interpreting findings within the context of the political economy of health care, illuminates how (unpaid) navigational, managerial and information work is generated but goes largely unacknowledged by the system, which increasingly relies on the contributions of families (Barken et al., 2016; Armstrong et al., 2001; Bookman & Harrington, 2007). A primary contribution of this study is in fact, an exploration of how structural constraints and neoliberal ideologies inform caregiver experiences of the health care transitions of older adults.

Policy & Practice

In the immediate, there is a need for further care management or navigational support from the health care system; whether the expansion of the system navigator role, or the addition of a different type of support. Regardless, these positions should incorporate the medical, social and emotional wellbeing of a care recipient – reflecting a whole person perspective of wellness as opposed illness (Quehenberger & Krajic, 2017; Fries, 2019). As such all efforts should be made to encourage equity of services, and not necessarily only equality.

Incremental changes may be more palatable due the neoliberal priorities prominent in health care reform. More feasible changes that could address some of the issues that caregivers were experiencing could involve updating governmental websites. If up to date and adequate information is provided to caregivers on how to navigate, it could not only allow for easier transitions for them, but also remove some of the strain for those working within the system. Additionally, small changes directed at making care truly person-centred could relieve some of the added burden and stress facing caregivers, like ensuring clothing is labeled before residents are moved into a PCH. System navigator positions could be expanded to provide more support for families throughout the transition process, however, this involves adding one more person to a system that already has a significant number of individuals caregivers must interact with to ensure proper navigation and care is received. These are steps that are tangible and easy to implement, that do not require an ideological shift. However, these steps do not detract from the information work and structural burden facing caregivers, and instead aim to position them to be better “educated consumers”.

To further address the systemic challenges and burdens that caregivers experience when transitioning someone into a PCH, health systems need to take caregivers needs and perspectives into account, such as through integrating families more fully into system re-design (beyond current advisory council mechanisms) or adopting caregiver friendly policies throughout health systems. Although the 2011 Caregiver Recognition Act (Bill 42) provided an opportunity, it was focused more on promote awareness and understanding of care work; moreover “a policy framework did not develop, and findings from Manitoba’s caregiver consultations (designed to inform the act’s implementation) were posted quietly online, yet never formally publicly released or discussed” (Funk & Obedzinski, 2019). Furthermore, legislation such as this at a provincial level, absent of allocated funding, is also limited in its ability to change operational policies of health authorities.

More broadly, better coordination across health care systems should be considered. Doing so would transform the private or individual struggle of families, to a public responsibility for providing a model of care that mitigates the navigational burden experiences of many caregivers.

Caregivers often expressed they were doing as much as they could, and that this was still not enough to keep their loved ones safely in the community. For many, institutionalization is seen as a last resort, only to be considered once all other options and services have been exhausted in the community. This public perception is fueled by a policy and practice emphasis on ageing in place, and PCH placement only when absolutely necessary, bolstered by theories of successful aging through independence, and a number of nursing home media scandals circulating in public awareness (Lloyd et al., 2014; Armstrong & Daly, 2017). Additionally, the quality of care can vary drastically between PCHs (Doupe et al., 2019). Yet despite the negative perception of long-term care facilities, they have always been a necessary component of the health care system; more so, one would argue, in the current context. The framing of PCHs as a last resort places undue pressure on caregivers to avoid PCHs through all available means and at all and any costs. Given this, an ideological shift, both systemic and cultural, is needed regarding the role and function of PCHs. Armstrong and Daly (2017), for instance, provide many strategies in this regard, and emphasize the importance of offering choice. Here I outline six adapted factors Armstrong and Daly (2017) that focus on the move in to residential care that could impact the perception of these facilities being a “last resort”:

1. Adequate numbers of available PCH beds so those who need care have choice in terms of where and when to move
2. Eligibility criteria that takes into consideration the burden that caregivers are encountering when attempting to maintain someone in the community
3. Locating PCHs near where residents live and work. Care homes should not be tucked away or hard to travel to, but should be integrated into everyday life
4. Allowing for physical spaces that encourage choices. This included private rooms and/or shared, outdoor spaces, and kitchen facilities so residents can make their own food and keep engaged in life fulfilling activities

5. Ensure there is enough staff to allow variation from rigid routines. Allowing for personalized care and not task- and time-based activities provides the opportunity for much needed social and emotional care in PCHs
6. Ensuring that caregivers are given the option of whether or not to provide care in facility. Many caregivers spoke about the care they provided as necessary to ensure their family member received it, not as something that they wanted to participate in to ensure the basic daily needs of older adults were being met.

Making institutionalization a positive choice requires positive experiences. This could involve regulated or standardized entrance procedures for facilities, where a social worker or senior staff member are required to be present and walk through the facility with family members. To diminish the feelings of isolation from the community programs upon entrance into a PCH, a care manager could help ensure consistent monitoring once a resident is moved into a facility to ensure families feel supported, and their concerns are addressed post move.

Lastly, at the broadest level, change requires an ideological shift in what health and health care should be – what Fries (2019) refers to as a "utopian vision" (pg. 3). This would require a reconceptualization of health, and a systemic shift from our current medical/pathogenic system to one of social medicine, or at the extreme of salutogenesis. Such a paradigm shift, from "sick care" (Segall & Fries, 2011) and a reactive "pathogenic paradigm" (Fries, 2019, pg. 3) has important implications for both home care and PCHs. Home care, for example, is a program for individuals who have been assessed as requiring a particular level of assistance with a particular task and are assigned a health care aide or personal support worker to assist them in that task, with no deviation allowed from the plan. This however depends on individuals reaching a point of decline at which they need assistance. Once home care has been initiated, instead of performing rehabilitative or restorative home care (a goal of care in other countries but could be implemented here) to improve the functioning of individuals, often they are provided “care” that maintains them at their current level. Care in PCHs is again directed at provided task-based activities. Care provision is provided by professional (Registered Nurse, Licenced Practical Nurse), and non-professional (Health Care Aides, Personal Support Workers) staff members. Individuals are typically scheduled for when they get up, get ready for the morning, and receive baths or showers. In this, care is also fragmented between staff member types, and not a team based approach. Individuals in both settings are not given the time, supervision, or prompting to be able to perform their own care; the system promotes a sense of learned helplessness that generates further decline rather than helping people maintain their function, and feel socially valued (Fries, 2019).

Havens (1995) contends that the continuum of long-term care should be “characterized by ‘open’ or permeable boundaries rather than rigid boundaries and discrete criteria” (pg. 252). Care plans should be made with the individual and their care providers, she argues, as opposed to current processes of assessment and gatekeeping (Havens, 1995). Moreover, traditional models of care delivery award primacy to the needs of the system, when individuals do not fit within the confines in how care is provided, they are expected to change to fit the needs of the system, however, more socially rooted models of care provide the stimulus for system to fit the client (Havens, 1995). Social models of care thus incorporate the needs of the older adult and their family members as the focus of care planning. The collaborative nature of care planning (including “a broad range of health care workers”), provides a “social model of delivery systems [that] are seldom hierarchical” (Havens, 1995, pg. 258). A shift to a more social model of care could be a first step towards incorporating more salutogenic properties throughout the health care system, while reducing the reliance on medical dominance and pathogenic perspectives.

LIMITATIONS

During data collection for this project, the WRHA was in the midst of the panel re-design process. As a result, there was only limited amount of system navigators working in the region that were only implemented to specific geographic areas. There was only one community navigator, and it was unclear how many hospital navigators were present, as reports from service provider placed this number anywhere from 3 to 6 in the city. As a result, it is unclear if transitions were improved or further complicated for families. Lack of publicly available information on program implementations make it unclear if the panel redesign has been further implemented, to what extent, etc.

The participants in this study tended to have high socioeconomic status, as such there was under-representation of disadvantaged groups of carers. This lack of diversity made it difficult to understand the experiences of disadvantaged caregivers. The latter may lack cultural health capital (Shim, 2010), and experience potentially even more challenges.

Secondary data analysis made returning back to caregivers or service providers for further information or clarification impossible. That being said, both caregiver and service provider participants generally offered rich descriptions of transition-related interactions and experiences. Although interviewers did not specifically ask about paneling, it was raised in an inductive or emergent way by caregivers when discussing system navigation (which may in fact be a strength of the data).

The lack of publicly available policy documents in MB made policy analysis particularly challenging, and this challenge was not initially foreseen. Existing policy perspectives thus could only be derived from the narratives of service provider participants alongside publicly available information on websites.

OPPORTUNITIES FOR FUTURE RESEARCH

Future research could tie caregiver accounts of navigating transitions to concepts such as social exclusion (Grenier & Guberman, 2009), as well as collect data about the transitional experiences from caregivers from more diverse and/or marginalized backgrounds, including those who live rurally.

Additionally, since the panel process re-design was implemented in part so as to ease burden on caregivers, and allow for more consistent client/patient ‘flow’ into PCH, future research could evaluate the panel re-design to assess whether this initiative altered the systemic barriers that caregivers faced throughout this process, and whether this in turn affected caregiver burden and paneling decisions.

CONCLUSIONS

This analysis focused on understanding caregiver experiences of an interactions with the health care system when transitioning an older adult across the care continuum into a PCH. My findings highlight the structural burden that family caregivers encounter when navigating systems. For caregivers, successful transitions require much more than providing physical and social care; they require cultural health capital and information work. The additional work required to navigate exacerbates additional stress and burden during an already emotional time. The findings from this project can inform our understanding of caregiver experiences and struggles while navigating this transition (in particular the paneling process), and through highlighting the broader structural roots of these challenges, inform the development of strategies to more effectively begin to address this pressing issue.

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Appendix I: Family Caregiver Question Guide

Interview Guide:

Interviewer___________________________

Date_________________________________

Interview start time_________________________

Participant ID_________________________

---

1. **How long, in years, would you say you have been in a caregiving role with your [mom/dad/spouse/etc.]?_______________**
2. **What is [care recipient]'s primary condition for which they need your help? ____________________________________**
3. **What is [care recipient]'s age in years?__________________________**

3. About how many hours a week, on average, do you provide this kind of help for [care recipient]?_____________________

4. How many (if any) children do you have that still live at home with you? ___ How old are they?_____________

5. Are you employed? FT/PT/not at all/self-employed (how many hrs per week?_______)

6.What is your type of occupation?_____________________________

7. General place of employment?_____________________________________

So, now we are going to shift gears a bit, and the rest of the interview from here will be more conversational and open-ended. I'm interested in having you speak about your experience as a caregiver. I have a few questions to ask, but please feel free to talk about anything you think is important.

[Probe throughout about interface with the systems/policies: eg. Home care, what were the limitations/challenges; were there any groups or providers who were particularly helpful? Were there any services that you were not able to access? Were there any frustrating aspects of that experience?]

1. So, perhaps to start, could you **tell me how you help** your [mom/dad/spouse/etc.]. PROBES: Can you describe what you do? How has this changed over time? Who else helps?

2. **What has this [caregiving] experience been like** for you, so far? PROBES: feelings, stresses, rewarding/positive aspects, challenges.

3. What would you say is the **biggest struggle** for you in providing this help to your (mom/dad/spouse/etc.)? PROBES: seek clarification; why is it a struggle; examples of particularly challenging events, situations or times.

4. Would you say you **feel responsible for** [care recipient]? **If yes:** What is that like, to feel responsible for [care recipient]? PROBES: What does it mean to you, to feel responsible? What are the feelings involved with this responsibility? Examples? Tell me more…

5. Can you talk about a time when you helped [care recipient] **navigate through an organization, system or bureaucracy** (or done this on their behalf)? PROBES: what they did and how/why, what the experience was like to do this kind of navigational work, and how different policies and organizational practices affected their experience (and wellbeing). WRAP WITH: Do you have any other examples you'd like to share?

6. I'll turn now to ask you to focus on your employment. What has it been like for you to balance your job and your caregiving responsibilities? PROBES: do they work full time or part-time? Have you ever needed time off to provide care for [care recipient]? If so, how did they negotiate that; was their employer accommodating? How have policies and organizational practices affected their employment and caregiving experience (and well-being)? WRAP WITH: Do have any other examples you'd like to share?

7. Has your experience in navigating through these systems as a caregiver generally been similar or different to experiences in navigating through systems in other areas of your life? Could you talk some more about this/these other experiences?

8. **Is there anything else** you'd like to add? Anything that you've told me that you wish to clarify?

8. The next part of the interview is designed to measure how stressful caregiving is for you. I'm going to ask you a series of questions, please choose the response that best describes how you feel.

Please circle the response the best describes how you feel.	Never	Rarely	Sometimes	Quite frequently	Nearly always	**Score**
1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
2. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
3. Do you feel angry when you are around your relative?	0	1	2	3	4	
4. Do you feel that caring for your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4	
5. Do you feel strained when you are around your relative?	0	1	2	3	4	
6. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	

7. Do you feel that you don't have as much privacy as you would like because of caring for your relative?	0	1	2	3	4	
8. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
9. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
10. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
11. Do you feel you should be doing more for your relative?	0	1	2	3	4	
12. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	

1. How often do you feel that your relative (You can use the person's name or relation here e.g., 'your mother' instead of 'your relative' in each question, to personalize this) is safe and/or well cared for when you are not there?

1	All of the time
2	Most of the time
3	Some of the time
4	A little of the time
5	None of the time

2. How often have you had sleep disturbed because of caring for your relative?

1	All of the time
2	Most of the time
3	Some of the time
4	A little of the time
5	None of the time

3. How often have you been satisfied with the support your family has given you?

1	All of the time
2	Most of the time
3	Some of the time
4	A little of the time
5	None of the time

4. If we consider 4 categories where “1” is not lonely, “2” is moderately lonely, “3” is severely lonely, and “4” is extremely lonely, what do you consider yourself to be, most of the time?

1	Not lonely
2	Moderately lonely
3	Severely lonely
4	Extremely lonely

5. In general, would you say your health is:

1	Excellent
2	Very Good
3	Good
4	Fair
5	Poor

6. In general, would you say your mental health is:

1	Excellent
2	Very Good
3	Good
4	Fair
5	Poor

So, for the last part of the interview, I’m going to ask you just a few questions about yourself such as your age and education.

Gender: M___ F___ Transgender____

What is your age, in years? _____

What, if any, is your primary ethnic/cultural identification? _________________

What is your current marital status?

1	Single
2	Married
3	Common-law
4	Widowed

5	Separated/Divorced

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

Elementary school or less____

Some high school____

High school graduate____

Some college (including CEGEP) or trade school____

Diploma from college or trade school____

Attended university____

University degree____

Post-graduate degree____

Other (please specify)___________

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

Below $19,999/year___

$20,000 - $39,999/year___

$40,000 – $59,999/year___

$60,000 - $79,000/year___

$80,000 - $99,999/year___

$100,000 or more___

Appendix II: Service Provider Question Guide

BASE Question Guide for Qualitative Interviews with Service Providers

NOTE: Some additional questions may be asked of participants that are specific to their area of expertise. *For instance, those in self/family managed care might be asked to consider barriers that families have in trying to access the program, as well as the challenges they face in documentation, coordination and so on after acceptance. Those in home care might be asked about barriers that families face accessing types of home care services. Those in the PCH system might asked about challenges that families have in understanding and accessing the paneling process (e.g., and differences between hospital or community).*

1. Can you tell me a little bit about the **nature of your position and the work that you (and your organization)** do/does with family caregivers?
    a. I'm particularly interested in the ways you might help family caregivers **"navigate the system" on behalf of the care recipient**. (**Probes:** tell me more; examples; could you explain? What types of resources do you refer them to?)

    b. How would you **define** system navigation? (**Probes** – what does it include?)

    c. What do you feel are the **advantages or disadvantages of your position/role (or your organization's role) for your ability to help family caregivers navigate systems**?

2. Based on your experience, when family caregivers are navigating systems, **what are some of their most common experiences?** (**Probes:** tell me more; examples; could you explain? What does the process involve, for them?)
    a. What aspects of the system do caregivers **ask the most questions about or tend to seek the most help** with?

    c. What do you think are family caregivers' **greatest challenges** in system navigation; What are the sources of these challenges?

    c. In your experience, what tends to **make it easier** for family caregivers to navigate systems?

3. Based on your experience, **do some types, or even groups of family caregivers struggle more with system navigation, and why?** (**Probes:** tell me more; sources of advantage as well as disadvantage; examples; could you explain?) AND followup:
    a. How do you think these family caregivers could best be helped?

4. Thinking more broadly now, we are interested in why there might be a need to help families navigate these systems. What do you think it is about these systems themselves that create this need? AND followup:

    a. Are there any **changes we can make to** these systems, to **practices or policies** that could help?

5. Is there anything else you'd like to add?

6. Is there anyone else you'd recommend we speak to about this topic? (e.g., other providers in town that do system navigation work, especially private consultants)